Illness Representations and Psychological Well-Being in Adults with Type 1 or Cystic Fibrosis related Diabetes.

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Declaration

I declare that this thesis has been composed by me and that the work herein is my own. This piece of work has not been submitted for any other degree or professional qualification.

Signed

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Abstract

Introduction:
Illness representations and psychological well-being were investigated in two patient groups diagnosed with insulin dependent diabetes; Type 1 diabetic patients, and patients with diabetes secondary to cystic fibrosis, a pre-existing, life threatening, genetic condition. The purpose of this study was to compare the illness representations held by patients to investigate whether differences in perceptions of consequences and control existed between groups. This study also investigated whether patients' perceptions of illness played a role in levels of anxiety and depression and whether differences in illness representations existed between patients and their health care teams.

Method:
Participants completed self-report questionnaires measuring illness representations of diabetes and levels of anxiety and depression. All eligible participants were sent the study pack to their home address by post. A total of 22 cystic fibrosis related diabetes (CFRD) and 45 Type 1 diabetes patients completed and returned the questionnaires. Age, duration of diabetes and recent blood glucose level (HbA1c level) information was obtained for each participant. All participants were over 16 years of age. In addition, a total of 17 staff, working within the adult cystic fibrosis service completed an adapted version of the Illness Perceptions Questionnaire.

Results & Discussion:
There were no significant differences between the two patient groups on perceived consequences or treatment control of diabetes. Contrary to prediction, the CFRD group perceived significantly lower levels of personal control over their diabetes than the Type 1 group ($p<.01$). This finding may, in part, be due to the CFRD patients' perception of their diabetes as a largely uncontrollable consequence of the progression of their cystic fibrosis. No associations were found between illness representations and levels of anxiety and depression in the CFRD group, however perceived consequences and treatment control were predictive of levels of depression, measured by the Well-being Questionnaire, in the Type 1 group (Adjusted R squared = .208, $p = 0.016$). Differences existed between the staff group and the CFRD patient group on perceived consequences of diabetes (<.001) but staff and patients' beliefs converged on perceived levels of control. Clinical implications and future research recommendations are discussed.

1. Introduction

1.1 Overview

As research into medical illnesses advances and treatments improve, more people are living with chronic medical conditions, which although cannot be cured, can be managed with ongoing treatment regimes. In this climate of medical advances, patients and their families may have increasing expectations that all medical problems are curable. Given such expectations, accepting the personal consequences of a chronic medical condition and embracing self-management of illness can be difficult. The goal in chronic illness (Holman & Lorig, 2000) is not cure, but rather the maintenance of a pleasurable and independent life for the affected individual.

Improved treatments are leading to prolonged life, but what is the impact of living with a chronic medical condition on psychological well-being and quality of life? Inherent in chronic illness is uncertainty, indefinite outcomes and often having to cope with a dynamic and progressive disease course. The individual with a chronic condition has to adapt to coping with their illness, a situation that often requires a significant degree of self-management.

The physical and psychosocial functioning of individuals with the same medical conditions varies widely, suggesting that there is a huge variation in the subjective impact of a chronic medical condition. It is generally accepted that 20-25% of individuals with a chronic medical problem experience significant psychological symptoms (White, 2000). Contributors to the psychological impact of illness may include the stigma of ill health, functional limitations and the consequent impact of

limitations on independence and role, the need for behavioural changes as well as the negative impact that the problem has on the individual's daily routine.

This variation in subjective impact has been investigated in terms of the ways in which patients make sense of and respond to the threat carried by their illness. The Self-Regulation Model developed by Leventhal and colleagues attempts to explain this variation and proposes a number of stages the individual goes through when faced with illness (Leventhal, Meyer & Nerenz, 1984). The present study was interested in this variation in psychological adjustment to chronic illness, specifically focussing on insulin dependent diabetes, and used Leventhal's model to investigate the cognitive representations people hold of their illness.

One reason why diabetes has become a target of research in health psychology is because understanding patients' perspectives on their illness should lead to ways to foster better self-management (Hampson, 1997). This study will investigate psychological adjustment and illness representations in individuals with insulin dependent diabetes but is specifically interested in the relative impact of the condition on two different patient populations. It compares the psychological well-being and representations of illness in a group of Type 1 insulin dependent diabetics with no other medical problems with a group of patients diagnosed, in childhood, with Cystic Fibrosis (CF), a life-threatening, genetic disease, who have subsequently developed insulin dependent diabetes as a secondary complication to their CF.

Psychological adjustment to chronic medical problems is important as it can impact on the individual in a number of ways; on mood, behavioural responses, disease course and outcome, and ultimately quality of life, independent of the effects of the medical disorder. Previous research has shown an increased risk of developing a depressive illness in individuals with diabetes compared to the general population (Anderson, et al 2001b) however the impact of a secondary diagnosis of diabetes on individuals with a pre-existing chronic illness is not yet known. The current study aimed to investigate this with reference to cystic fibrosis.

1.2 Diabetes Mellitus

Facts and Figures

Diabetes mellitus is a relatively common chronic condition for which there is currently no known cure. Individuals suffering from diabetes experience elevated blood sugar levels that need to be controlled with dietary restriction and/or medication. There are two main forms of diabetes, insulin dependent diabetes mellitus (IDDM) and non-insulin dependent diabetes mellitus (NIDDM). About 3% of the adult UK population has a diagnosis of diabetes, of which 10-25% are IDDM (Diabetes UK, 2003). Internationally, diabetes mellitus is a serious chronic condition for about 2% of the world population with prevalence expected to rise over the next decade (Surgenor, Horn, Hudson, Lunt & Tennent, 2000). It is the seventh leading cause of death in the USA (Hampson, 1997).

Diabetes has stimulated research due to the importance of its self management regime as well as the reported relatively high risk of developing depression in

individual's with diabetes in comparison to the general population (Anderson et al 2001b). Management of diabetes aims to optimise the individual's glycaemic control in order to avoid short term risks such as seizures and coma as well as to delay or prevent long-term complication of diabetes i.e. neuropathy, heart disease, renal disease and retinopathy.

Causes and Complications

IDDM, also known as Type 1 diabetes, usually appears before the age of forty. In Type 1 diabetes, cells in the pancreas are destroyed resulting in them being unable to produce any, or sufficient amounts, of the hormone insulin, which is required for the uptake, storage and release of glucose in the body. Without insulin, the body is unable to utilise the glucose ingested by the individual or released by the liver, subsequently the body is unable to turn glucose into the energy the body requires. As a result, blood glucose levels rise producing hyperglycaemia leading to symptoms of excessive urination, thirst and weight loss. Complications resulting from increased blood glucose levels include damage to the kidneys and eyes as well as increased risk of coronary heart disease, stroke, circulation problems and nerve damage. If left untreated high glucose levels may lead to coma and eventually death (Diabetes UK, 2003; Hampson, 1997).

Management

Management of Type 1 Diabetes aims to replace the body's faulty production of insulin by injecting insulin into the body. People with this type of diabetes commonly take either two or four injections of insulin each day (Diabetes UK,

2003). The individual diagnosed with insulin dependent diabetes will be required to self administer daily insulin injections for the rest of their life. Combined with this, the individual must monitor their blood glucose levels as well as continuously manage their diet and exercise. Blood glucose monitoring, involving obtaining a drop of blood by pricking the finger, should be done at least once a day. The goal of treatment is to keep blood glucose levels within the normal range, preventing levels from going high (hyperglycaemia) or dropping too low (hypoglycaemia). Both hyperglycaemia and hypoglycaemia can have serious consequences if left untreated. Complications of hyperglycaemia are mentioned above whereas hypoglycaemia, if left untreated, can cause seizures or coma. Management of diabetes is aimed at limiting and preventing both the short and long-term complications by keeping blood glucose levels within a target range i.e. HbA1c <8%.

1.3 Cystic Fibrosis

Facts and Figures

Cystic Fibrosis (CF) is the UK's most common life threatening, inherited, disease. It affects around 7,500 children and adults in the UK and approximately 1:2500 live births (Hill & Temple, 1998). The disease is caused by mutations to a single gene, discovered in 1989, called the Cystic Fibrosis Transmembrane Conductance Regulator (CFTR) gene, essential for regulating salt and water movements across cell membranes. Until relatively recently, individuals born with CF were not living past childhood or early adolescence, however, treatment advances in recent years have improved life expectancy and now well over half of people born with CF live beyond the age of 30. The life expectancy of those with CF has increased in many

countries probably as the result of increased availability of medication, overall rigorous care and the diagnosis of milder forms of the disease. The early treatment of newborns screened for CF as well as well-organized CF centres that provide regular and coordinated care appear to be important elements in the improved care and survival of patients (WHO, 1994).

Symptoms and Complications

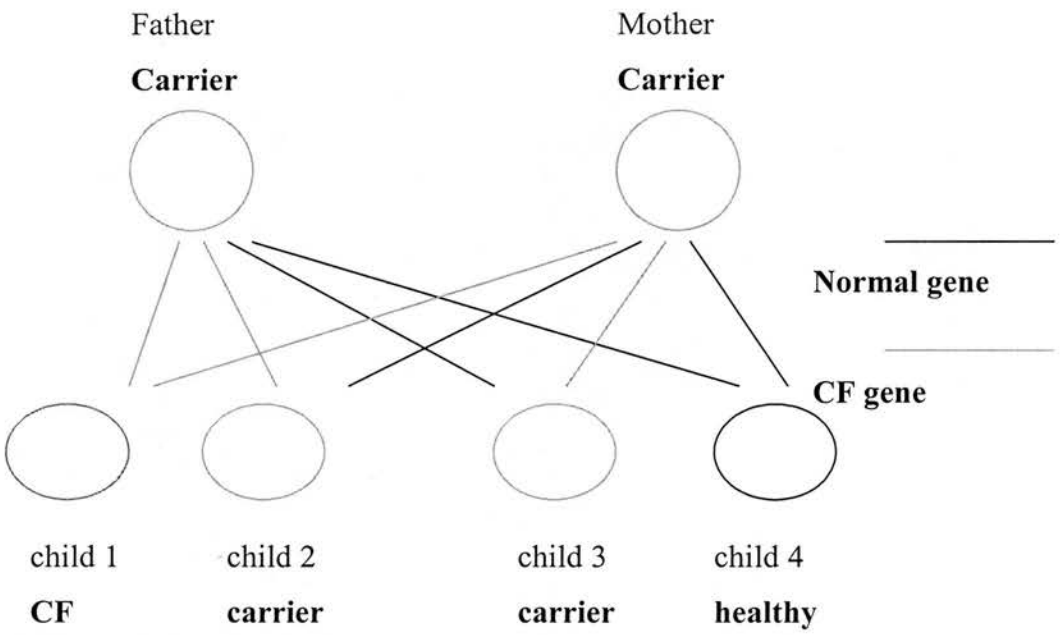
Faulty regulation of salt and water across cell membranes results in people with CF producing thick, sticky mucus, which clogs the lungs and digestive system making it difficult for individuals with CF to breathe and absorb food properly. Pulmonary hypersecretion blocks airways leaving CF patients vulnerable to chronic bacterial infections and frequent exacerbations. Patients often have repeated or chronic lung infections requiring intensive antibacterial therapy. In addition, a wide range of nutritional problems are associated with CF, which can lead to malnutrition in patients and can result in growth retardation, delayed puberty, pulmonary disorders, malabsorption, poor immune status and finally the adverse progression of the disease (WHO, 1994). Symptoms and complications lead to recurrent infection, bronchial damage and ultimately death from respiratory failure.

Why is a baby born with Cystic Fibrosis?

A baby is born with CF only if both parents are carriers of the defective CF gene. If both parents are carriers of the defective gene each child born has a one in four chance of being born with CF, similarly each child has the same one in four chance of being perfectly healthy and a two in four chance of being a carrier of the defective

CF gene. If the child is born a carrier, the child will be perfectly healthy but may pass the faulty gene onto its own child. In the UK, one person in 25 is a carrier (Cystic Fibrosis Trust, 2002). This genetic link is illustrated in Figure 1.1. There are many different mutations of the CF gene, indeed over 1000 different mutations of the CF gene have been discovered. The variation in the severity of symptoms experienced by CF patients can be partly explained by the types of mutations they carry. Seventy-five percent of people with CF in the UK carry two of the most common gene mutations, ΔF 508.

Figure 1.1: The genetic aetiology of Cystic Fibrosis
(adapted from Hill & Temple, 1998)



Management

There is currently no cure for cystic fibrosis, therefore management is aimed at slowing or preventing the secondary effects of the disease. Chest physiotherapy is

fundamental to CF management as airway clearance techniques aim to remove the excess mucus that clogs the lungs and improve ventilation. Production of pancreatic enzymes, which help to break down food in the digestive system, is deficient in approximately 90% of patients with CF (Gavin, 1998). Consequently, these patients are required to take additional enzymes with food to prevent malabsorption. A variety of oral medications will be given daily, including prophylactic antibiotics to help fight infections, fat soluble vitamins and often inhalers and nebulizers to use pre and post physiotherapy sessions.

The effective management of CF is more complex than simply complying with a set medical regimen. Patients must routinely monitor their symptoms and interpret changes as a basis for modifying their personal therapy or seeking additional medical input (Parcel, Swank, Mariotto, Bartholomew, Czyzewski & Sockrider, 1994). People with CF face a complex and time-consuming daily routine including physiotherapy, exercise, medication and dietary supplements.

1.4 Cystic Fibrosis related Diabetes (CFRD)

Facts and Figures

With advances in treatment and improved levels of care there has been a resulting increase in the life expectancy of individuals born with cystic fibrosis. This has resulted in a corresponding increase in the number of patients developing diabetes as a secondary complication mainly because insulin production becomes deficient owing to increasing pancreatic disease. The incidence and prevalence of impaired glucose tolerance and diabetes in CF patients is difficult to determine due to lack of

routine monitoring at most CF centres, however, incidence does appear to increase with age with reports of 43%-50% prevalence in patients with CF aged over 30 (Lanng, Thorsteinsson & Lund-Andersen, 1994a; Moran, et al 1998). The majority of patients with CFRD are diagnosed at around 18-20 years of age (Azzopardi & Lowes, 2003; Dodge & Morrison, 1992).

Management

Cystic fibrosis related diabetes is slightly different from Type 1 diabetes as the onset of symptoms is usually more gradual and ketoacidosis (the acid bodies that result from the breakdown of body fat when there is insufficient insulin to allow adequate passage of glucose from the blood into the cells of the body) is rare. However, it remains important to achieve optimum blood glucose levels in patients with CFRD as hyperglycaemia may adversely affect weight and pulmonary function and result in the development of microvascular complications (Azzopardi & Lowes, 2003). Evidence exists to suggest that the complications of CFRD increase mortality, can cause deterioration in respiratory and nutritional status and can have a profound impact on the clinical course and survival of patients (Milla, Warwick & Moran, 2000; Wilson, Kalnins, Stewart, Hamilton, Hanna, Durie & Pencharz, 2000). The introduction of insulin therapy for these patients has been shown to improve lung functioning and reverse detrimental decreases in body mass index (Lanng, Thorsteinsson, Nerup & Koch, 1994b).

Some CF centres now carry out glucose tolerance tests routinely to monitor for pancreatic insufficiency. An abnormal glucose tolerance test will not automatically

result in the need for insulin treatment, for example, if nutritional status and weight are well maintained. However, when insulin therapy is indicated a diagnosis of CFRD presents patients with an additional burden, as they are required to understand and adhere to yet another complex and demanding treatment regime. As with Type 1 diabetes, management of CFRD includes regular blood glucose monitoring and the need for daily insulin injections.

1.5 Chronic illness and distress

Prevalence of Psychological Distress

What evidence exists to indicate a high prevalence of psychological distress among individuals with physical illness? As previously mentioned, it is widely accepted that between 20-25% of people with a chronic medical problem experience significant psychological problems (White, 2000). This figure may be reduced to around 15% for general medical outpatients (Guthrie, 1996). In addition, it has been suggested that research studies investigating and reporting on prevalence rates of psychological morbidity in medical populations may actually underestimate true values of distress due to the common psychological defence of denial. Denial used as a coping strategy by people with medical illness may result in blocking out awareness of the loss or threat imposed by the illness and repressing thoughts and emotional responses (Nichols, 1984). A recent Scottish Executive Paper, Health in Scotland (2000), supported these figures stating that around a quarter of medical patients experience significant levels of anxiety and depression and highlighted the need for recognition of psychological problems in this population.

Demands of Chronic Illness

Chronic illness presents individuals with a number of challenges and demands. Diagnosis of a chronic illness may challenge the individual's views and beliefs about the world in which they live and it brings with it the challenges of accepting and adapting to the personal consequences of illness, coping with self-management of the condition and forming workable relationships with medical and care staff. These increased demands in combination with limited personal resources can leave patients vulnerable to psychological problems.

With illness comes the experience of threat, not just in relation to the immediate problems but also with regard to future concerns. Chronic illness is often synonymous with uncertainty and this can prove distressing and problematic for many patients. In addition there is often a lack of control over the situation that undermines feelings of personal security. The experience of loss both with regard to the specific consequences of the illness or disease as well as in relation to the loss of key roles is another common reaction. Personally important and valued occupational, social and sexual roles can be hard to maintain and can result in significant psychological distress. Patients may be left feeling isolated and unsupported. The individual's beliefs and understanding of the world as a safe, fair and controllable place may be undermined.

Early Psychological Research in Medical Settings

Studies carried out a number of years ago with general hospital patients revealed high levels of psychological distress. Moffic and Paykel (1975) screened 150

medical inpatients using the Beck Depression Inventory and concluded an overall prevalence of clinical depression of 28.7%. Maguire et al (1974) implemented screening questionnaires with 230 consecutives admission to two medical wards. Twenty three percent of the sample met criteria for a psychiatric diagnosis. Hawton (1981) subsequently followed up this sample after 18 months and identified that about half of the sample recognised as having a psychiatric diagnosis at baseline remained so during the follow up period.

Psychosocial Adjustment to Chronic Illness

More recent studies have supported these earlier findings and similarly highlighted the vulnerability of individuals suffering from chronic illnesses to psychological distress. Findings from one study (Huure & Aro, 2002) focussed on the long term psychosocial effects of chronic illness suggested that adults with persistent chronic illness which limited their daily life, reported more depression and lower self-esteem than healthy controls. Similarly another study found a strong association between presence of a chronic medical condition and psychological distress (Koopmans & Lamers, 2000).

Several studies that have focussed on the relationship between chronic illness and psychological well-being have suggested that chronic illness has an indirect impact on psychological well-being via the increased demands placed on the individual (Hough, Brummit & Templin, 1999; Vilhjalmsson, 1998). One study, conducted in Iceland, suggested that domestic, occupational and financial strains are aggravated by the presence of a chronic illness that in turn undermines personal resources

(Vilhjalmsson, 1998). Similarly, results of a study carried out in the United States (Hough et al, 1999) suggested a model whereby chronic illness had no direct effect on depression but rather had an indirect impact on the demands of the individual that led to decreased social support and increased depression.

On the contrary, results have also been reported that found that psychological adaptation amongst patients with a variety of chronic illnesses, including arthritis, diabetes, cancer, renal disease and dermatological disorders showed remarkably effective psychological adaptation and did not differ significantly from the general population on scores of psychological status (Cassileth, Lusk, Strouse, Miller, Brown & Cross, 1984). In addition, evidence has been provided that showed that chronic illness is associated with increased emotional distress and suicidal ideation in females, but not males (Suris, Parara & Puig, 1996).

Despite conflicting findings, what remains important is that psychological factors in chronic illness are present and they should not be ignored. The psychological ramifications of chronic illness are often overlooked as many patients do adjust well to their situation. However, for others adjustment is not so easy and as Nichols (1984) emphasised "it is vital to remember that for some the anguish of the emotional reaction is harder to bear than the illness itself".

A comprehensive review of the literature on the association between chronic illness and psychological well-being is beyond the scope of the present study, however the evidence available provides confirmation that psychological factors in chronic illness

play a substantial role. The current study is primarily interested in the psychological adaptation to chronic illness in two specific patient populations, Type 1 diabetes and cystic fibrosis related diabetes, it is to these groups that we now turn.

Psychosocial adjustment to Cystic Fibrosis

Cystic Fibrosis has a profound impact on both the lives of people with the disease and their families. The illness is the sum of its physical symptoms as well as its psychological and social consequences (Aspin, 1991). Researchers who have investigated the psychosocial adaptation of individuals with CF have found varying results. Studies interested in childhood adaptation to the disease vary from conclusions that children with CF are as well adjusted as their healthy peers (Drotar, Doershuk, Stern, Boat, Boyer & Matthews, 1981; Cappelli, McGrath, Heick, MacDonald, Feldman & Rowe, 1989; Kashani, Barbero, Wilfrey, Morris & Shepperd, 1988) to suggestions that psychiatric diagnosis is more common in children with CF compared with a healthy control group (Steinhausen & Schindler, 1981) and findings that 53% of a sample of 36 children with CF had a psychiatric disorder (Steinhauser, Schindler & Stephan, 1983). Another study provided evidence that although children with cystic fibrosis generally did not demonstrate more symptoms of psychological disturbance than a comparative healthy group, they did show levels of worry, poor self-image and anxiety comparable with that of a group of psychiatrically referred children (Thompson, Hodges & Hamlett, 1990).

Some of this variation in findings has been put down to methodological limitations, including the use of small, biased samples, unstandardised questionnaires, the

absence of comparison groups and inappropriate statistical methods (Lask, 2000). A meta-analysis carried out by D'Angelo, Fosson and McAninch (1991) concluded that children with CF were as well adjusted as healthy children and children with other chronic illnesses. Over recent years, there has been a significant improvement in the life expectancy of children with CF, resulting in suggestions that the improved physical ability of younger children with the disease has perhaps altered attitudes and expectations of these children and their parents contributing to better psychological adjustment (Norman & Hodson, 1983).

Adolescence is a time of physical, emotional and cognitive growth. Like any other adolescent, an adolescent with CF must adjust during this time of transition, but in addition, he/she must also learn to cope with his/her cystic fibrosis. Adapting to CF in adolescence may involve taking more personal responsibility for treatment and adapting to the social limitations of the disease. Research focussing on adolescent adaptation to CF has again generally tended to highlight how well psychologically adjusted adolescents with CF are (Blair, Cull & Freeman, 1994; Bywater, 1981; Moise, Drotar, Doershuk & Stern, 1987; Straker & Kuttner, 1980). However, inconsistencies in the literature are still present; one study (Sawyer, Rosier, Phelan & Bowes, 1995) concluded that female, but not male, adolescents with CF were significantly less well adjusted on 11 different measures of self image compared with healthy controls.

Much of the literature focussing on psychological adjustment to cystic fibrosis has concentrated on children and adolescents. However, as diagnostic practices improve

and treatment advances, the life expectancy of individuals born with CF has similarly improved. Cystic fibrosis is no longer a disease limited to childhood, but presents a variety of different psychosocial problems for the individual as he/she approaches adulthood. However, in contrast to the relatively extensive literature focussing on children and adolescents, there is relatively little research investigating the psychosocial impact of CF in adulthood. The literature that is available again provides conflicting evidence. Strauss and Wellisch (1981) found that 43% of their CF sample were depressed occasionally or frequently and Pearson, Pumariega and Silheimer (1991) noted a higher prevalence of clinically significant levels of psychiatric symptoms in their CF sample than would be expected in the general population. This evidence would suggest that there is a substantial level of psychological distress in this population. However, in contrast, the finding of Cowen, Corey, Simmons, Keenan, Robertson & Levison (1984) and Moise et al (1987) suggested that adults with CF have adequate psychosocial adaptation and Shepherd, Hovell, Harwood, Granger, Hofstetter and Molgaard (1990) found no significant differences on four psychosocial measures between their adult CF patients and a healthy control group. More recent studies carried out in Israel and the US, have similarly provided evidence of good psychological adaptation in adult CF populations (Anderson, Flume et al 2001b; Blau, Livne & Mussaffi, 2003).

Psychosocial Adjustment to Diabetes

A diagnosis of diabetes involves patients having to accept the need for a change in lifestyle and to accommodate to the psychological and behavioural demands of the illness (Delamater, Jacobson, Anderson, Cox, Fisher & Lustman, 2001; Jacobson,

1996; White 2000). Patients may find the prospect of the disease and its treatment daunting due to the daily management regime, the acknowledgement of the risk of complications and the possibility of later physical health problems. Diagnosis of the illness presents patients and their families with new challenges and constraints and for some can lead to a sense of sadness and loss (Jacobson, 1996). In 1989, representatives of government health departments and patient organizations from all European countries met in St. Vincent, Italy under the auspice of the World Health Organisation/International Diabetes Federation. As a result of this meeting guidelines and recommendations were laid down under the St Vincent Declaration (Krans, Porta, Keen & Staehr Johansen, 1995), in an attempt to improve both the clinical and social care of people with diabetes. Included in this declaration were guidelines to improve the psychological well-being of diabetic patients.

In a recent review (Jacobson, Samson, Weigner & Ryan, 2002) and a meta-analysis (Anderson et al, 2001a) evidence has been provided that the risk of experiencing comorbid depression or depressive symptomatology is increased in those individuals with diabetes compared with the general population. Each presentation of depression has been shown to have adverse effects on social and physical functioning and on quality of life, that are independent of the effects of the medical illness (Jacobson et al, 1997). Anderson et al (2001a) calculated odds ratios to compare the odds of developing depression in diabetic samples with the odds of developing depression in non-diabetic samples. Their results concluded that from the 39 studies and combined total of 20 218 subjects they reviewed, a diagnosis of diabetes doubled the odds of developing depression. In addition this finding generalized across gender as well as

community and clinical settings. Aggregate lifetime prevalence of major depression based on the studies they reviewed was given at 28.5%. This is significantly higher than the estimate of 17% lifetime prevalence rate of depression in the general population (Hammen, 2001).

The reason for the increased prevalence of depression in diabetic samples compared to the general population is not fully understood. Two dominant hypotheses suggest that either (1) depression occurs directly as a result of the biochemical changes due to the illness or its treatment, therefore mood disturbance is due to the direct physiological effects of the medical condition or (2) depression occurs as a result of the psychological demands or psychological factors related to the illness or its treatment, suggesting that depression results from the increased stresses and strains of having a chronic illness, difficulties with adaptation and adjustment to treatment and often debilitating complications, and the perceived burden/disability of the illness (Talbot & Nouwen, 2000). Investigation into these hypotheses suggests that neither is conclusively supported (Talbot & Nouwen, 2000) nor are the two mutually exclusive. Rather, a complex interaction between genetic, biological, social and psychological factors is likely to be involved.

Whether the prevalence of depression is higher in diabetics than other individuals with a chronic illness is questionable. Although a recent study (Kessing, Nilsson, Siersma & Anderson, 2003) suggested prevalence of depression was not elevated in people with diabetes compared with other chronic illnesses, this study only compared diabetic individuals with one other patient group, patients with osteoarthritis, and

despite very large samples sizes, only looked at admission rates for depression as the measure of rate of depression. This measure inevitably focussed solely on the more severe cases of depression and ignored the mild/ moderate cases of depression that, although still significant, may have been treated on an outpatient basis or indeed not treated at all.

Although less studied, research has similarly shown that anxiety disorders are common amongst adults with diabetes and that again they may occur more often in diabetic patients than in the general population (Jacobson, 1996; Lustman 1988; Peyrot & Rubin 1997). Symptoms of hypoglycemia associated with poor diabetic control can be similar to the autonomic symptoms associated with anxiety, for example, shaking and sweating, and for this reason, patients may find it difficult to discriminate between hypoglycemia and anxiety and the two conditions may be confused. Patients may be anxious about their illness and about their ability to adapt to the treatment and the management regimens that are inherent in the condition. In addition they have to live with the knowledge that the risk of developing later complications is directly related to the success with which they are able to integrate changes into their lifestyle (White 2000).

A comorbid diagnosis of a psychological disorder in diabetes may interfere with efforts to achieve optimal glycaemic control either via behavioural or physiological pathways, and therefore is an important factor both in diabetes management and overall quality of life. The presence of psychological problems can compromise the individual's ability to engage in optimal self-management, resulting in increasing

medical complications and perhaps exacerbating psychological difficulties. A diagnosis of diabetes may influence psychological health, which, in turn, may influence the patient's ability to address self-management demands (White, 2000). The psychosocial impact of diabetes was recognised, in one study, as a stronger predictor of mortality in diabetes patients than a number of frequently used clinical and physiological outcome variables including HBA1c level, previous hospital admissions and previous heart attacks (Davis, Hess & Hiss, 1988).

Despite the awareness of an increased prevalence of depression, and perhaps anxiety, in diabetic populations, recognition and treatment of the disorders has been limited in clinical practice. Promisingly, successful treatment for depression in diabetic patients whether pharmacological (Lustman, Griffith, Clouse, Freedland, Eisen & Rubin, 1997, Lustman, Freedland, Griffith & Clouse, 2000) or psychological (Lustman, Griffith, Freedland, Kissel & Clouse, 1998) is possible and has been shown to be associated with improvements in glycaemic control. Interventions that can help improve self-care and optimise glyceamic control could potentially result in fewer complications and ultimately an improved quality of life. This evidence suggests that there is an important association between psychological well-being and medical outcome.

Better awareness, recognition and treatment of psychological problems are important in themselves but could also contribute a key element in the outcome of diabetes management and care. A treatment approach that incorporates an understanding of the social and psychological as well as the medical ramifications of diabetes should

be encouraged and where psychological problems exists these should be addressed and, where appropriate, suitable interventions implemented.

1.6 Psychological Factors in Adjustment to Illness

Illness Representations

The literature provides evidence that the physical and psychosocial functioning of individuals with chronic medical conditions varies widely and suggests that a number of mediating variables, including age, gender, illness severity, family functioning, socio-economic status, parental health, social supports and coping style may contribute to this variability (Lask, 2000). In addition, the role of psychological factors in terms of how individuals appraise and made sense of the disease/injury has been highlighted as an important factor in an individual's adjustment to illness.

The self-regulatory model (Leventhal, Meyer & Nerenz, 1984) seeks to explain this variation in subjective response to illness and disease. The model focuses on how an individual represents and responds to the threat carried by illness. In their original work, Leventhal and colleagues carried out interviews with both chronically ill and healthy individuals. These interviews gave the researchers an insight into what they called the "common sense beliefs" individuals held about their illness (Leventhal et al, 1984). They proposed that these underlying "common sense" beliefs consisted of several different dimensions and provided patients with a framework in which they were able to understand and cope with their illness. Leventhal and colleagues originally defined these beliefs along five dimensions as outlined below:

- *Identity*: Referring to the label (i.e. diagnosis) given to the illness and the symptoms.
- *Cause*: The perceived cause of the illness, i.e. biological, genetic, psychosocial.
- *TimeLine*:The patient's beliefs about the likely time course of the illness, i.e. is it acute or chronic.
- *Consequences*:The perceived impact of the illness for the patients eg. in physical or emotional terms.
- *Curability/controllability*: The patient's beliefs about how well the illness can be managed or cured.

Work by other researchers using a variety of different patient groups and methodologies, has consistently provided support for these five dimensions outlined by Leventhal's original work (e.g. Baumann, Cameron, Zimmerman & Leventhal, 1989; Bishop, 1987; Lau, Bernard & Hartman, 1989).

Leventhal's self regulatory model of illness behaviour

Leventhal incorporated his model of illness cognitions into a model of illness behaviour in an attempt to explain the relationship between an individual's cognitive and emotional representations of their illness and their subsequent coping behaviour. This model is called the 'Self-Regulatory Model of Illness Behaviour'.

The model is based on problem solving principles and expands on social-cognitive theory of health behaviour. The model suggests that when an individual is faced with illness, they deal with this in the same way as they would any other problem they faced, and in dealing with the problem/illness the individual would go through a number of different stages.

Stage 1 involves interpretation of the problem. In the case of ill health, interpretation of the problem requires making sense of the information available in order to develop an understanding of the health threat. Interpretation is based on information taken from a number of different sources concerning the nature of the illness. The self-regulatory model takes account of pre-existing knowledge and understanding of illness suggesting that cognitive representations of illness do not arise 'de novo'. Appropriately, the model takes account of social and environmental factors, placing the individual in context and acknowledging the crucial roles that these factors play in the interpretation of signs and symptoms of illness (Bennett, 2003). Information available includes the signs and symptoms of the illness, information the individual has gleaned from doctors, friends and others in the social sphere as well as the individual's prior knowledge and experience of illness. The model proposes that an amalgamation of this information is cognitively represented along the dimensions outlined above.

Leventhal's model incorporates a parallel processing response giving equal salience to both the individual's emotional and cognitive response to a health threat. The model takes account of the interplay between the cognitive and emotional responses to illness, acknowledging that the emotional impact of illness on the individual may contribute to their cognitive interpretation of symptoms (Easterling & Leventhal, 1989).

Stage 2 of the self-regulatory model involves the individual adopting coping strategies to deal with the problem in order to regain a state of normality. Adaptive coping must address both the cognitive and emotional responses to the threat to health. Once coping strategies have been adopted, the third and final stage of the model involves appraisal of the strategies used; how successful or unsuccessful have they been in achieving the desired state? The recursive nature of this model suggests that the three different stages will continually interact until the coping strategies are appraised as successful and the desired stage of equilibrium has been regained. An assumption of the Self-Regulatory model is that when a problem or change to the status quo is encountered, the individual will be motivated to solve the problem and return to the state of normality. This model is illustrated in Figure 1.2.

Unlike other models adopted in health psychology that provide models of health-behaviour decision making, for example, the Health Belief Model, the Self Regulatory Model focuses uniquely on how individuals represent and respond to the threat of disease.

Evidence in support of the role of illness representations

A number of studies have investigated the predictive power of the Self-Regulatory Model and the role of illness representations in adaptive outcome. The model suggests that illness representations may predict mood, behavioural responses to illness and, where behaviour will influence the disease process, the model may predict disease outcome (Bennett, 2000). One of the original assumptions of self-regulation theory was that coping acted as a mediator between illness representations

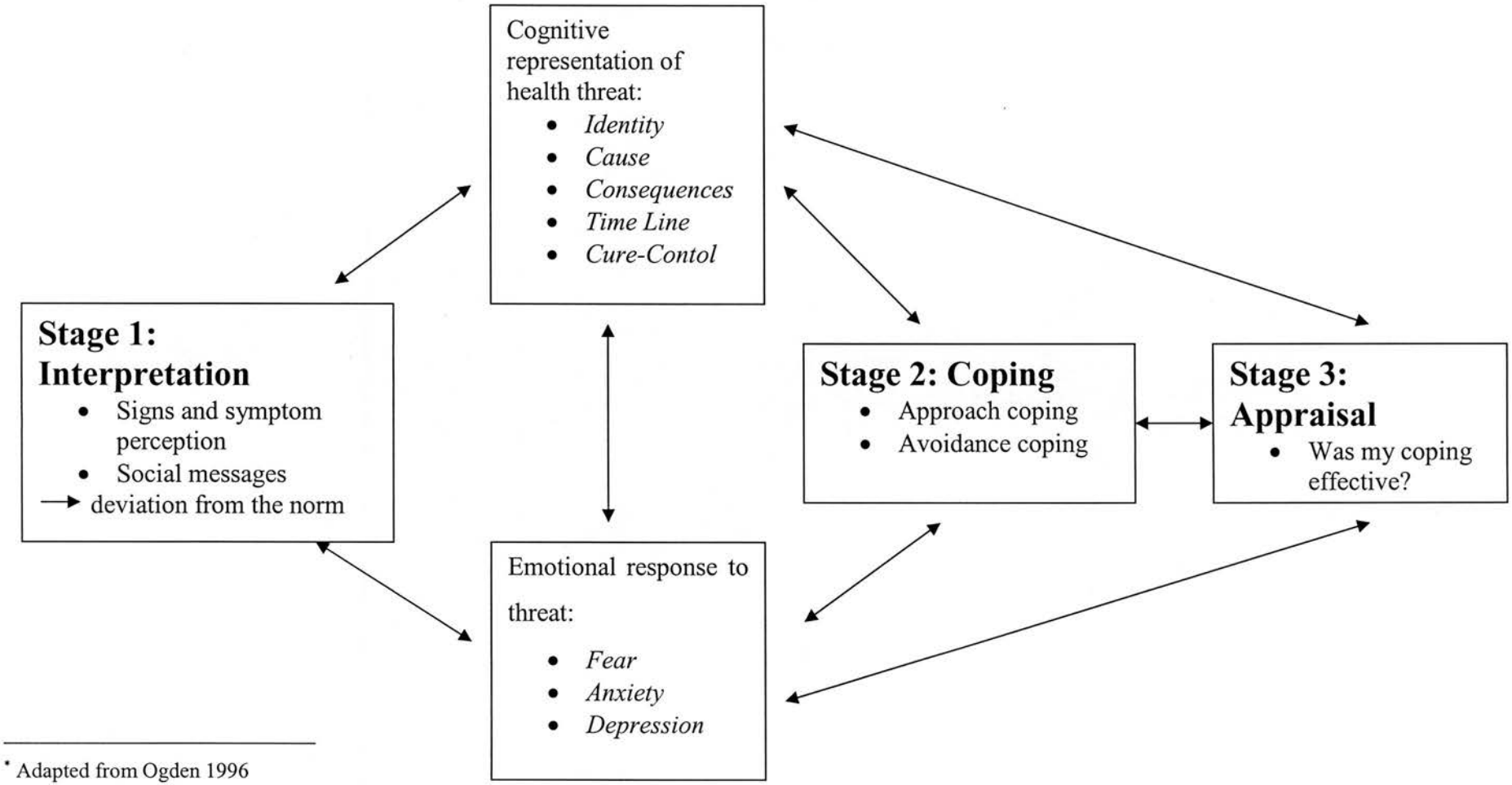
and outcome, however there has been limited support for this mediating role in the literature (Heijmans, 1998; Kemp, Morley & Anderson, 1999; Rutter & Rutter, 2002; Scharloo, Kaptein, Weinman, Hazes, Willems & Bergen, 1998). Nevertheless, researchers have suggested that illness representations are associated with outcome relatively independently of coping and have highlighted the importance of illness representations in exerting a direct influence on adaptive outcome.

Researchers have examined the roles of illness representations in adaptive and psychosocial outcome in individuals with chronic disease. Studies have looked at the role of illness representations in a variety of different illnesses including Irritable Bowel Syndrome (Rutter & Rutter, 2002), Epilepsy (Kemp et al, 1999), Multiple Sclerosis (Jopson & Moss-Morris, 2003; Schiaffino et al, 1998), Chronic Fatigue Syndrome (Heijmans, 1998; Moss-Morris, 1997) Rheumatoid Arthritis (Scharloo et al, 1998; Schiaffino et al, 1998) and Chronic Obstructive Pulmonary Disease (Scharloo et al, 1998). Results have confirmed the contribution of illness representations to variance in adaptive outcome over and above the influence of illness severity.

Illness representation dimensions relating to identity, control and consequences appear to be of particular importance, with a stronger illness identity, belief in serious consequences and perceived low levels of personal control being predictive of worse outcome. In patients with chronic fatigue syndrome and multiple sclerosis, those who believed their illness to be serious, that they had little or no control over it and saw little possibility of a cure, reported greater mental health problems and less vitality than those with the opposite set of beliefs (Heijman, 1998, Schiaffino et al,

1998). A review of literature examining illness perceptions in patients with chronic illness suggests that perceived consequences and control are important factors influencing medical and psychological outcome (Heijmans, 1998; Jopson & Moss-Morris, 2003; Rutter & Rutter, 2002; Scharloo et al, 1998). Studies assessing the control dimension, possibly the most studied illness representation dimension, show that perceived internal control is positively related to various indices of medical, psychological and behavioural well-being (Scharloo & Kaptein, 1997).

Figure 1.2: Leventhal's Self Regulatory Model of Illness Behaviour*



* Adapted from Ogden 1996

Illness representations and diabetes

A number of studies have used the Self-Regulatory Model to investigate behaviours and outcome in patients with diabetes. Studies carried out by Hampson and colleagues in the 1990's appear to be the first published studies, in the field of diabetes, that have assessed the five components of illness representations, explicitly using the Leventhal framework. They compared cognitive representations to various aspects of self-management (Hampson, Glasgow & Toobert, 1990; Hampson, Glasgow & Foster, 1995). These studies were prospective and controlled for demographic and medical history variables in order to strengthen the conclusions that could be drawn about the role of illness representations as determinants, rather than correlates, of self-management (Hampson 1997). The first of these studies investigated a sample of women with non insulin dependent diabetes (NIDDM) (Hampson et al, 1990). Illness representations, in their study referred to as 'personal models', were assessed using a comprehensive interview including both open-ended and fixed response questions. Results of this study suggested that personal models contributed significantly to the prediction of one aspect of self-management, diet, but were not predictive of self-monitoring behaviours, medication taking or blood glucose control. Of the personal model constructs, treatment effectiveness was the most important predictor of dietary self-management.

A further study was carried out several years later to extend this initial study by including both male and female participants (Hampson et al, 1995). Again, the sample population had a diagnosis of non insulin dependent diabetes and a similar methodology was employed. In this later study, the interview was slightly adapted in

order to improve the internal consistency of the personal model constructs. Again, results suggested that personal model constructs, especially treatment effectiveness, were significant predictors of diet, both concurrently and prospectively, and beliefs regarding cause and treatment effectiveness significantly predicted blood glucose levels.

The authors concluded that the illness representations framework could be extended to work in diabetes both as a way of describing individual differences in diabetes beliefs and as a way of contributing to the understanding of diabetes self-management. However, there were limitations to these studies. The authors described their studies as including all five dimensions of the illness representations outlined by Leventhal, however, in practice the studies used only 3 personal model constructs namely, cause, seriousness and treatment effectiveness. In their work, the time-line and consequences representations were collapsed into one single construct called 'seriousness' and the causal representation consisted of just three items which assessed only the extent to which the patient blamed him/herself for the onset of his/her diabetes.

The Hampson et al studies although beginning to explicitly use the Leventhal framework to assess illness representations used only self management and medical markers as outcome variables, they did not take account of psychological adaptation. Subsequently, Watkins and colleagues, again examined the relationship between cognitive representations of diabetes and diabetes-specific health behaviours, but in addition their study looked at quality of life variables as an outcome measure

(Watkins, Connell, Fitzgerald, Klem, Hickey & Ingersoll-Dayton, 2000). The study involved a large number of adult participants (n=296) and included both non insulin dependent and insulin dependent diagnoses. The results of this study lent additional support to the importance of illness representations as predictors of health behaviours but also to predictors of quality of life. Specifically, the results highlighted that the patient's understanding of their diabetes as well as their perceived levels of control over their diabetes were significant predictors of engagement with diabetes specific health behaviours and positive perceptions of quality of life. However, interestingly the findings suggested that adherence to treatment regimens did not necessarily improve quality of life. The authors hypothesised that perhaps good adherence to treatment management may negatively impact on quality of life due to an increased perceived burden.

Although the study does lend support to the importance of illness representations not only as predictors of health behaviours but also as predictors of quality of life, the study was conducted as a secondary analysis of data and it did not use a validated or reliable measure of illness representations. Similarly, the illness representation constructs they used were slightly different from definitions used elsewhere; causal beliefs were related to changes in blood glucose level as opposed to the initial onset of the diabetes and consequences assessed beliefs regarding the likelihood of medical complication as opposed to social and financial consequences as addressed elsewhere in the literature. Unlike the Hampson et al studies the authors did not assess for duration of diabetes nor illness severity and therefore these factors were not controlled for in the results.

In 1996, Weinman and colleagues developed a questionnaire for assessing illness representations (Weinman, Petrie, Moss-Morris & Horne, 1996). Although Leventhal argued that interviews were the preferred method to examine beliefs as they allowed cognitions to be subject generated rather than researcher generated, this questionnaire enabled researchers to access a greater number of participants. Completion of a questionnaire is far less time-consuming than an interview. The measure, called The Illness Perception Questionnaire, included all five of Leventhal's original constructs and provided a well validated and reliable measure by which to investigate illness representations. A comprehensive review of studies using the measure, highlighted some problems with internal consistency and therefore the questionnaire was revised several years later to improve the reliability of the measure and to include an emotional representation construct which although integral to the self-regulatory model, had been left out of the original version (Moss-Morris, Weinman, Petrie, Horne, Cameron & Buick, 2002).

A study carried out by Law et al in 2002 was the first to use this revised measure in a population with diabetes (Law, Kelly, Huey & Summerbell, 2002). The study examined the relationship between illness beliefs, diabetes self-management behaviours and psychological well-being in a population of adolescents with insulin dependent diabetes. Analyses concluded that the adolescent participants perceived their diabetes to be of chronic duration and they believed that they had high levels of personal control over their illness. They perceived moderate levels of treatment control and moderate consequences of diabetes on their lives. There were no gender

differences in the illness representations held and neither age nor illness duration was significantly associated with any aspect of illness beliefs (Law et al, 2002). Unlike other studies (Hampson et al, 1990, 1995, Watkins et al 2000) illness beliefs did not significantly account for variance in any of the self management behaviours however, illness beliefs were found to be important predictors of psychological well-being. Perceived consequences of diabetes was a significant positive predictor of anxiety and the personal control construct was a significant predictor of positive well-being.

The generalisability of this study is limited by the small sample size, and the use of a standardised adult questionnaire, the Well-Being Questionnaire, to assess psychological well-being in adolescents. However, it does again support the association between illness representations and psychological well-being in individuals with diabetes and suggests that cognitive variables may prove valuable targets for intervention.

Both the Watkins et al (2000) and the Law et al (2002) studies used a cross-sectional methodology, therefore relationships between variables cannot be understood as causational and this method does not capture the dynamic interplay of the self-regulatory model. A longitudinal study would be a more satisfactory method of investigating the relationship between illness representations and outcome variables. A study by Skinner and colleagues looked at illness representations, and social support as predictors of self care behaviours and well-being (Skinner, John & Hampson, 2000). Fifty-two adolescent participants with insulin dependent diabetes

completed assessment measures at baseline and at six month follow up. Results found that overall girls experienced higher levels of anxiety and depression symptoms than boys but neither age, duration of illness nor socio-economic status was associated with psychological well-being. The perceived impact of diabetes was a significant positive predictor of anxiety and depression and a significant negative predictor of psychological well-being. Changes in perceived levels of social support from baseline to follow up were similarly predictive of psychological well-being. Personal model constructs assessing perceived seriousness and control were significant predictors of dietary self-management.

The most recently published study to lend support to the role played by illness representations in the psychological well-being of individuals with diabetes suggests that the perceived impact of and identity with the illness is significantly associated with depression and anxiety symptoms and is negatively associated with positive aspects of psychological well-being. Beliefs in treatment effectiveness in this study were also significantly associated with positive psychological well-being (Edgar & Skinner, 2003). Again, this study investigated the role of illness representations in adolescents with insulin dependent diabetes. The role of coping as a mediating variable between illness representations and psychological well-being was investigated, however, no robust evidence was found to support this mediating role bringing into question Leventhal's original model that illness representations determine coping strategies. These results suggest that illness representations are more predictive of psychological outcomes than coping strategies.

1.7 The social context of illness representations

Just as the social network of a chronically ill patient may be affected by the illness, so the response of the social network may influence a patient's health related beliefs and behaviours (Croyle & Hunt, 1991). The process of developing illness representations does not take place within a vacuum, but rather is an inter-personal as well as intra-personal process. Leventhal's model is particularly useful in this context as it acknowledges the role of social factors in the appraisal of illness and explicitly states that information from significant others may be especially important during the appraisal stage (Leventhal et al, 1984). Beliefs held by people within a patient's social network, expressed in the form of advice or opinions, can affect the patient's illness representations and health related behaviours.

The self-regulatory framework needs to be extended into the social context (Law, 2002; Leventhal et al, 1997), however, to date there has been relatively little research done to integrate illness beliefs and representations into the interpersonal context. The role of family members in shaping particular illness beliefs has been investigated by a small number of researchers who have investigated the extent to which patients' and spouses' beliefs about illness differ and to what extent this impacts on the patient's psychological well-being and adaptation to illness (Heijamns, de Ridder & Bensing, 1999; Law, 2002, Richards, Fortune, Chong, Mason, Sweeney, Main & Griffiths, 2004; Salewski, 2003).

Diverging views on an illness can constitute a great source of stress (Leventhal et al 1985). Heijmans et al (1999) carried out a cross-sectional study comparing the

illness representations held by patients suffering from Chronic Fatigue Syndrome or Addison's Disease with those held by their spouses. The findings provided evidence that where there was dissimilarity in a couple's illness representations this had an impact on the patient's coping and adaptive outcome. Richards et al (2004) investigated dissimilarity in illness representations held by patients with a chronic medical condition and their partners and included a measure of psychological distress for both the patient and their partner. Their findings provided evidence that divergence in patients' and partners' beliefs were significantly associated with levels of psychological distress in both patients and their partners.

Law (2002) investigated dissimilarity in adolescent and maternal representations of Type 1 diabetes. He found that adolescents' and their mothers' beliefs about illness converged on all but two of the illness representation dimensions. Mothers perceived that their adolescent's diabetes had significantly more serious consequences and had a significantly greater emotional impact on their child than the adolescents themselves did. This study did not find any association between dissimilarity across illness representations and adolescent psychological well-being, however it did suggest that the high degree of consistency in the beliefs of adolescents and their mothers may be of benefit to their psychological well-being.

A similar study compared illness representations held by patients and their health care providers (Heijmans, Foets, Rijken, Schreurs, de Ridder & Bensing, 2001). The importance of the relationship between patients and their health care providers has been recognised as important in the management of chronic disease, but prior to this

study there had been little attempt to systematically compare patients' and providers' perceptions of the consequences of a chronic disease. As Leventhal has commented, many aspects of our common sense representations of illnesses emerge from our interpretations of the information to which we are exposed during medical encounters (Leventhal et al, 1997).

Heijmans and colleagues studied a sample of 580 patients and their GPs and asked them to complete questionnaires about the stressors associated with the patient's illness (Heijmans et al, 2001). Their findings provided evidence that patients and doctors often diverge in the way they think about illness. In their sample of patients with osteoarthritis, doctors judged the disease as more serious than the patients themselves. The results suggested that the perceptions of illness held by GPs were more congruent with medical knowledge than with the experiences of patients. Heijmans et al (2001) propose that differences between the perceptions of patients and health-care providers about the stressors confronting patients with chronic disease may lead to misunderstandings and disrupt effective communication. In addition they found that incongruence in patients' and GP beliefs were greater where treatment was less clear and that incongruence between patient and GP was association with worse health status of the patient.

In view of this and in light of the fact that there is currently no clear treatment protocol in the management of CFRD, one question addressed by the current study was to what extent differences in illness representations of diabetes existed between the cystic fibrosis patients and the staff involved in their care. The CF population

generally have long-standing and, at times, intensive contact with their medical team and therefore understanding and effective communication between parties is of utmost importance in the provision of good quality care.

As the incidence of diabetes increases in the CF population, a greater understanding of the beliefs held by patients about this condition together with a greater insight into staff perceptions of this illness should lead to ways to foster better communication and adjustment in this client group. The current study will focus specifically on beliefs regarding consequences and control of diabetes in comparing the illness representations held by patients and staff.

1.8 Summary

A greater understanding of patients' beliefs about their illness should lead to ways to foster better adjustment (Law, 2002). The mediating role of coping strategies within the Self-Regulatory Model is questionable, nevertheless, previous research has highlighted the direct role of illness representations in predicting psychological adjustment. To date, research interested in the association between illness representations and psychological well-being has been conducted with adolescents and adults with both Type 1 and Type 2 diabetes.

Since the development of the revised Illness Perceptions Questionnaire (Moss-Morris et al, 2002), diabetes research using the measure has focussed on adolescent adjustment to diabetes and the measure has not yet been used with an adult sample. In addition, there appears to be no research investigating illness representations and

psychological adjustment to diabetes in patients with a pre-existing chronic illness, as is the case for patients with diabetes diagnosed as a secondary chronic complication to cystic fibrosis.

Table 1.1 Summary of studies investigating the role of illness representations in diabetes

Study Authors	Sample demographics	Measures used	Illness Representation Constructs Investigated	Results
Hampson et al (1990)	N= 46 Female NIDDM Mean age = 57	Personal Models of Diabetes Interview Summary of Self-Care Activities	Seriousness (time-line + consequences) Symptoms Cause Treatment Effectiveness	Treatment Effectiveness predictive of dietary self-management
Hampson et al (1995)	N = 78 Male & Female NIDDM Mean age = 70	Personal Models of Diabetes Interview Profile of Mood States General Health Survey Summary of Self-Care Scale	Seriousness Cause Treatment Effectiveness	Treatment Effectiveness predictive of dietary self-management
Watkins et al (2000)	N = 296 Male & Female NIDDM & IDDM Mean age = 52	Diabetes Care Profile (234 item questionnaire assessing: attitudes/beliefs self-management behaviours Quality of Life	Consequences Cause Control (personal)	Higher perceived control associated with better adherence to diet Fewer negative feelings More positive feelings Less interference with social and personal functioning

Study Authors	Sample demographics	Measures used	Illness Representation Constructs Investigated	Results
Skinner et al (2000)	N = 52 Male & Female IDDM Mean age = 15	Well-Being Questionnaire Summary of Self-Care Schedule Diabetes Family Behaviour Checklist Diabetes Inventory of Peer Support Personal Models of Diabetes Questionnaire	Treatment Effectiveness (control and prevention) Consequences (seriousness and impact)	Perceived impact associated with psychological well-being Perceived control and seriousness associated with dietary self-management Higher perceived seriousness associated with poorer dietary management
Law (2002)	N = 30 Male & Female IDDM Mean age = 15.5	Well-being Questionnaire Illness Perception Questionnaire – Revised Summary of Diabetes self-care activities Questionnaire	Identity Time-line Consequences Cause Time-line cyclical Personal Control Treatment Control Illness Coherence Emotional Representation	Illness Beliefs not associated with any self-management behaviours Consequences predictive of anxiety Personal control predictive of positive well-being
Edgar & Skinner (2003)	N = 70 Male & Female IDDM Mean age = 15	Well-being Questionnaire Diabetes Illness Representation Questionnaire Kidcope	Identity Timeline Consequences Treatment Effectiveness	Perceived impact and identity positively associated with depression and anxiety Perceived impact and identity negatively associated with positive well-being Treatment effectiveness significantly associated with positive well-being

1.9 Aims

The aims of the current study were to investigate the relationship between illness representations, as defined by the Self-Regulatory Model, and psychological adjustment in patients with insulin dependent diabetes. The study aimed to compare the relative representations of illness held by patients with Type 1 diabetes with those held by patients with cystic fibrosis related diabetes and to determine whether differences in perceptions of consequences and control existed. As patients with cystic fibrosis have had experience of adapting to an existing complex and time-consuming daily treatment regimen it was hypothesised that the demands placed on these patients, by the additional stressor of diabetes, would have less impact than the similar demands placed on patients diagnosed with diabetes with no previous experience of chronic illness or self-management.

The study also aimed to determine whether, as had been shown in previous research, illness representations of diabetes were predictive of subjective measures of anxiety and depression.

Finally, the study aimed to move the Self-Regulatory framework in to the social context by assessing the illness representations of diabetes held by staff working with the cystic fibrosis population. Little is known about how illness representations form or how social interactions affect patient's ideas and beliefs, however there is speculation that where there is a mismatch and individuals do not share a common illness model, that adherence and psychological well-being is affected. This view has been supported in previous studies exploring patient's and spouse's beliefs

(Heijamns et al, 1999) and patient's and general practitioner's beliefs (Heijmans et al, 2001). Anecdotally, medical staff involved in the care of patients with cystic fibrosis related diabetes assume that the additional diagnosis will bare little additional impact on the patient. The current study aimed to investigate staff representations of the consequences and control of diabetes in their patients and to compare staff beliefs with those held by the patients themselves.

1.10 Hypotheses

Hypothesis 1

Cystic Fibrosis patients will perceive fewer consequences and more control of their diabetes than Type 1 Diabetic patients.

Hypothesis 2

Low perceived control and high perceived consequences will be associated with higher levels of anxiety and depression in both groups.

Hypothesis 3

Differences will exist between staff and patients' illness representations on dimensions of consequences and control.

2. Method

2.1 Design

Study Design

A between-subjects design was used.

Calculation of Power and Effect Size

In order to ensure power at 0.8, to detect a large effect size with $\alpha = 0.05$, the necessary sample size required for two equal groups would be 26 participants in each sample group (Cohen, 1992). However, as there was a finite population of 31 eligible patients with a comorbid diagnosis of cystic fibrosis and insulin dependent diabetes attending the clinics, power of the study was ensured by increasing the number of participants in the Type 1 diabetic sample.

Participants

The samples were recruited from the outpatient lists of three adult clinics in two large general hospitals in Edinburgh and Tayside. Eligibility criteria were individuals aged between 16 and 56 with a diagnosis of insulin dependent diabetes. Participants were drawn from two samples: (1) patients whose diabetes was secondary to cystic fibrosis (cystic fibrosis related diabetes) and (2) patients of a similar age, sex and duration of diabetes with a diagnosis of Type 1 diabetes. The upper age limit corresponded to the eldest individual in the cystic fibrosis sample, any older individuals in the Type 1 diabetes sample would be impossible to match. Patients were excluded if they had any other serious co-morbid medical condition or multiple diabetic complications.

A total of thirty-one potential participants with a diagnosis of cystic fibrosis related diabetes were approached of whom twenty-two agreed to participate, a response rate of 71 percent. One hundred and fifteen Type 1 diabetic patients were approached of whom 54 responded, a response rate of 47 percent. Two respondents from the Type 1 diabetic sample did not complete the questionnaires appropriately and seven respondents were excluded from the study due to the presence of multiple diabetic complications in six of the respondents and due to the presence of co-morbid psychiatric disease in one case. The final sample consisted of 22 participants with cystic fibrosis related diabetes and 45 participants with a diagnosis of Type 1 diabetes. The staff group working with the cystic fibrosis patients were also invited to take part in the study (n=25), 17 agreed to participate.

2.2 Procedure

Ethical Considerations

Ethical principles are concerned with protecting the rights, dignity and welfare of research participants. The major ethical principles in clinical psychology research are informed consent, avoidance of harm, privacy and confidentiality (The British Psychological Society, 2000; Barker, Pistrang & Elliot, 2002). The current study did not involve any element of deception, withholding of information or covert observation. All participants were provided with full information about the study including reasons for the research and what participation would involve before agreeing to take part. Participants were provided with an information sheet that outlined what the study was about, the study procedure, any potential risks or

benefits and a statement informing the individual that he/she was free to withdraw from the study at any time (Appendix A).

In addition, although the researcher was part of the cystic fibrosis team she did not have any direct therapeutic input with any of the participants with cystic fibrosis. The researcher was not involved in any way with the management or treatment of the participants with Type 1 diabetes. This allowed for free and informed consent of all participants.

All information provided was treated as confidential with only a number used to identify the participant. It was considered unlikely that the participants would suffer any harm as a result of participating in this study, however, participants were advised that should they encounter any problems, they should contact the researcher.

Ethical approval for the current study was obtained from the Lothian research ethics medical/oncology committee and the Tayside Committee on Medical Research Ethics.

Pilot Study

Ten eligible participants were sent an invitation letter and patient information sheet prior to clinic attendance. This explained the purpose of the research and made the participants aware of the likely presence of the researcher at their next clinic appointment. On arrival at the outpatient clinic, potential participants were approached by the researcher who reiterated the purpose of the study, explained

again what would be involved and asked each individual if they would be willing to take part. Those individuals who agreed to participate completed consent forms.

Demographic details were gathered for all participants. These consisted of the patient's age, sex, employment status, marital status, duration since diabetes diagnosis, and prescribed frequency of insulin injections.

The participants were given the option of completing the questionnaires in a quiet room beside the clinic or in the waiting area. This option was given in order that participants would not be reluctant to take part simply due to having to spend extra time at clinic. The researcher explained the instructions to each participant individually and remained on hand to answer any questions that might arise. Questionnaires took between 10 and 20 minutes to complete.

The pilot study highlighted a significant potential problem in that non-attendance at clinic appointments was not uncommon, particularly for the Type 1 diabetic group. In addition, Type 1 diabetic patients were only invited to the outpatient clinic every four to six months. Relying on eligible participants to attend their appointment would therefore have significantly limited recruitment. Consequently an amendment to the original methodology was formulated and approved by the relevant ethics committees.

Recruitment

This amendment involved accessing the hospital database to obtain home address details for all the eligible participants. In addition to the invitation letter and patient information sheet, each potential participant was also sent a personal information sheet, in order to gather demographic details, a consent form and the study questionnaire pack. Participants were asked to read the information and, if happy to participate, to complete the personal information, study questionnaires and consent form and return them to the researcher in the stamped addressed envelope provided.

Nurses working on the respiratory ward and therefore in contact with cystic fibrosis patients (n =15) as well as members of the adult cystic fibrosis team (n = 10) were asked to complete a short adapted version of the Illness Perceptions Questionnaire – Revised (see Appendix B). Members of the cystic fibrosis team were approached directly by the researcher and asked if they would agree to take part. Ward staff were approached by the charge nurse. A total of 8 members of the cystic fibrosis team and 9 ward staff agreed to participate and returned completed questionnaires.

2.3 Measures

Copies of all measures used are included in Appendix B.

Self-report questionnaires were presented in the same order to each individual participant. They are described in presenting order below:

The Well-Being Questionnaire (Bradley, 1994). This 22 item measure was developed specifically for use with diabetic patients. Each item is scored on a 0 to 3 Likert scale. It is designed to be particularly sensitive to the more cognitive symptoms of anxiety and depression and to minimise as far as possible the inclusion of somatic symptoms that may also be common in poorly controlled insulin-dependent diabetes. The measure consists of four sub-scales measuring anxiety, depression, positive well-being and energy. Reliability ratings suggest Cronbach alpha coefficients of 0.74, 0.67, 0.8 and 0.64 for each subscale respectively. It offers an advantage over the Hospital Anxiety and Depression Scale in that it provides a measure of positive mood state. The scale is increasingly being used for the purpose of auditing psychological outcomes in diabetes care and has been widely used in research examining illness representations and psychological well-being in patients with diabetes (Bradley 1994; Law, 2002; Law, Kelly, Huey & Summerbell, 2002). The author suggests that the scale may be useful to compare samples of people with diabetes with other patient groups (Bradley, 1994).

The Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983). This measure consists of 14 items divided into two subscales measuring depression and anxiety symptoms. The HADS specifically avoids items that measure physical manifestations of depression, as such items may lead to inappropriately elevated scores in populations of patients suffering from a medical condition. The scale was originally developed for use in general medical out-patient clinics but is now widely used in clinical practice and research. The subscales demonstrate good internal reliability with reported Cronbach's alpha scores ranging from .77 to .86 (Crawford,

Henry, Crombie & Taylor, 2001). The scale is short and easy to use and has good face validity.

The Illness Perceptions Questionnaire – Revised (Moss-Morris et al)

This measure was used to measure participants' illness representations. The original Illness Perceptions Questionnaire (Weinman, Petrie, Moss-Morris & Horne, 1996) was developed to provide a quantitative assessment of the five illness representation components, namely identity, consequences, timeline, control/cure and cause in Leventhal's Self Regulatory Model. However, a critical review of published studies using the measure revealed some variation in the internal consistency of specific subscales. The scale was subsequently revised to strengthen the psychometric properties of the original scale and to improve the reliability of the subscales. The revised questionnaire measures participants' illness beliefs along 9 dimensions. The control subscale was divided into two parts; personal control, the degree to which individuals believe that they can control/manage their symptoms, and treatment control, beliefs in the efficacy of treatment to control/manage their symptoms. Also, an additional timeline scale was developed to look at cyclical beliefs regarding illness variability and unpredictability, as well as acute/chronic timeline beliefs. Two further subscales were also included in the revised version taking account of emotional representations, an important component of the Self-Regulatory model that was overlooked in the original IPQ scale, and "illness coherence", to assess to what extent patients believe that they have a coherent understanding of their illness. All of the new subscales demonstrate good internal reliability with Cronbach alphas ranging from 0.75 to 0.89 (Moss-Morris et al, 2002).

The measure is divided into three sections. The identity scale is presented first and consists of commonly experienced symptoms. Patients are asked whether or not they have experienced the symptom since their illness and whether or not they believe the symptom to be specifically related to their illness. The next section specifically addresses identity, consequences, timeline, coherence and emotional beliefs. These are rated on a 5 point Likert type scale from strongly disagree to strongly agree. Finally, the causal dimension is presented in a separate section using the same Likert type scale. Overall the measure consists of 70 items.

Illness Perceptions Questionnaire – Revised: Adapted Staff Measure

One of the aims of the study was to determine whether staff beliefs about a diagnosis of diabetes were similar to those of the cystic fibrosis patients themselves. Specifically, the study aimed to determine whether beliefs about consequences and control of diabetes were similar between the staff and patient groups. To investigate this question an adapted version of the IPQ-R was developed for staff. Only the items concerned with consequences and control were presented to the staff sample. Wording on the staff questionnaire was based on advice from the original authors replacing "My diabetes" with " My patients' diabetes" (Moss-Morris, personal correspondence). This adapted staff measure consisted of 16 items and is enclosed in Appendix B.

Illness severity ratings:

Glyosylated haemoglobin (HbA1c). This reliable index of blood glucose control reflects average glycaemic control over the preceding 3 months (Marshall & Barth, 2000). This measure was used as an index of diabetes illness severity. The HbA1c level was monitored routinely at the clinic appointment as part of diabetes care and not especially for this study. The HbA1c level recorded most recently to the date that the patient completed the study questionnaires was used.

Forced Expiratory volume in 1 second (FEV1). FEV1 levels were used as a measure of illness severity in patients with cystic fibrosis. FEV1 measures the amount of air the individual can blow out of their lungs in one second, providing information about the state of the lungs. This measure is routinely taken at clinic as a measure of lung function. The health of the individuals' lungs is assessed according to how closely their FEV1 compares with that of a healthy individual of the same age and height. Table 2.1 shows a classification of CF lung disease severity. The FEV1 level used as a measure of illness severity in the current study was that recorded nearest to the date on which the patient competed the study questionnaires.

Table 2.1. Classification of Cystic Fibrosis Disease Severity

Mild	*FEV1 70%-90% of expected result*
Moderate	*FEV1 40%-69% of expected result*
Severe	*FEV1 less than 40% of predicted result*

2.4 Statistical Data Analysis

Statistical analysis was conducted using SPSS version 11.0 for Windows. All data were checked for assumptions of normality and homogeneity of variance before parametric analysis. Data that produced neither significant skewness nor kurtosis was assumed to follow a normal distribution (Tabachnik & Fidell, 1996).

Where exploratory data analysis revealed departures from normality and the data was positively skewed, logarithmic transformation was used to modify the data to fit the underlying assumptions of parametric statistics as recommended by Tabachnik & Fidell (1996). This was carried out for the following measures:

- The Hospital Anxiety and Depression Scale
- The Well-being Questionnaire Anxiety Scale
- The Illness Perceptions Questionnaire Dimensions:

  Timeline cyclical

  Emotional Representations

Where data was negatively skewed, reflection and logarithmic transformation was performed to modify the data. This was carried out for the following measures:

- The Illness Perceptions Questionnaire Dimensions:

  Timeline Acute/Chronic Dimension

  Personal Control Measure

Following transformation data followed a normal distribution.

Where data was skewed due to the presence of outliers, ie HbA1c level in the Type 1 group and duration since diagnosis in the CFRD group, these outliers were examined. Examination of the outliers could find no reasons for the atypical scores, therefore analysis was carried out both with and without the outlying values. Such analysis produced equivalent results allowing for confidence in the findings.

Student's t-test and one-way ANOVA analysis were performed to detect difference between groups. Pearson's Product Moment Correlation analysis was performed to detect associations between variables where the data was normally distributed. Spearman's rho correlations were performed on non-parametric data. To test whether illness representations could predict levels of anxiety and depression, stepwise multiple regression analysis was performed. For all tests carried out a significance level of $p < 0.01$ was set to protect the familywise alpha level and reduce the chances of making a Type 1 error due to multiple comparisons (Cohen, 1992).

Effect Size

The effect size gives a measure of the magnitude of the result independent of the sample size. Conventions proposed by Cohen (1988) arbitrarily define three levels of effect size, for the t-test of the difference between independent means these are defined as small 0.20, medium 0.50 and large 0.80. For the product moment correlation coefficient r, small, medium and large effect sizes are taken as 0.10, 0.30 and 0.50 respectively.

3. Results

3.1 Description of Sample population

Demographics

Gender, employment and marital status information is shown for both groups in Table 3.1. There were more males than females in the Type 1 diabetic group (M=60%, F=40%) but there was an equal split within the Cystic Fibrosis related diabetes (CFRD) group (M=50%, F=50%). The majority of Type 1 diabetic patients were in full time employment (76%) and this group included no students. In comparison, only 27% of the CFRD group were in full time employment, 27% were students and 32% were unemployed. Ability to work in the CFRD sample may be largely driven by the limitations of the disease, therefore this figure is likely to reflect the worse overall state of health in the CFRD group.

The majority of the Type 1 group were either married or living with a partner (47% and 20% respectively) whereas the majority of the CFRD group were living with parents (41%) with only 14% of this group married and 27% living with a partner. The mean age for the Type 1 group was 36.8 years and for the CFRD group 24.59 years, means and standard deviations for age are shown in Table 3.2. There was a significant difference in age between the two groups with the Type 1 group being significantly older than the CFRD group ($t = 5.502$, $p =<.01$). This difference in age may account for some of the variance shown in marital status.

Table 3.1. Frequency of gender, marital status and employment status by group N (%)

	Type 1 diabetics N (%)	CFRD N (%)
Gender		
Male	27 (60)	11 (50)
Female	18 (40)	11 (50)
Marital Status		
Married	21 (47)	3 (14)
Single	6 (13)	3 (14)
Living with Partner	9 (20)	6 (27)
Living with Parents	4 (9)	9 (41)
Divorced	1 (2)	0 (0)
Separated	3 (7)	1 (4)
Missing data	1 (2)	0 (0)
Employment Status		
Full Time	34 (76)	6 (27)
Part Time	7 (16)	3 (14)
Student	0 (0)	6 (27)
Unemployed	3 (6)	7 (32)
Missing data	1 (2)	0 (0)

Clinical Characteristics

Duration of Diabetes and Blood Sugar Level:

Means and standard deviations for duration of diabetes and blood sugar (HbA1c) levels are given in Table 3.2. Duration of diabetes data was missing for two participants in the Type 1 group and blood sugar level data was missing for one participant in the CFRD group. There was no significant difference between groups for duration since diagnosis ($t = 0.319$, $p = .751$). The Type 1 group included one outlier on the measure of blood sugar level though examination of this outlier could find no reason for this atypical result. T-tests were conducted with and without the outlier and both provided evidence that there was no significant difference between

groups (with outlier: t = 0.033, p = .974; without outlier: t = -0.195, p = .847) for HbA1c allowing confidence in this result.

Table 3.2. Means and Standard Deviations of Age, Duration since diagnosis (yrs) and blood sugar (HbA1c) levels by group

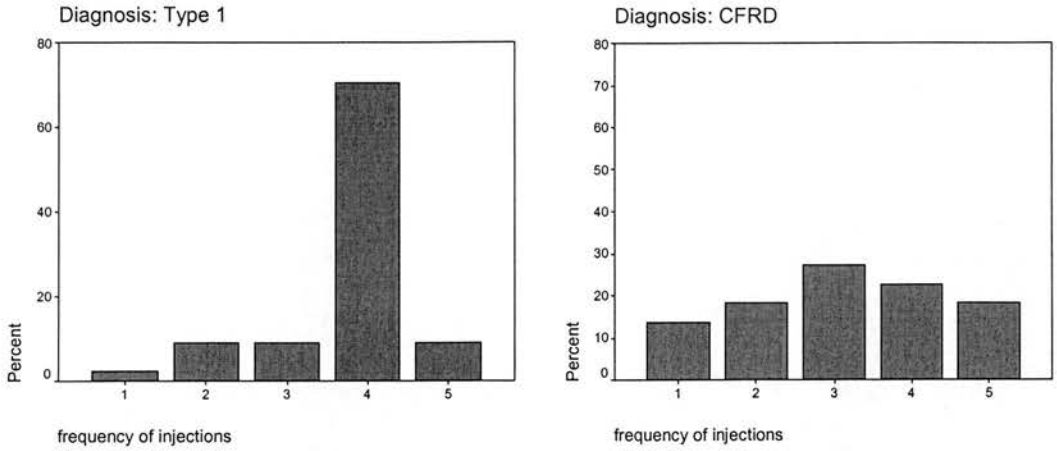
diabetes diagnosis		age	duration since diagnosis	blood sugar level
type 1 diabetes	Mean	36.80	4.98	8.11
	Std. Deviation	9.23	2.79	1.35
	Range	32	9.3	7.5
	N	45	43	45
CFRD	Mean	24.59	4.73	8.10
	Std. Deviation	6.84	3.38	1.97
	Range	23	14.7	7.3
	N	22	22	21
Total	Mean	32.79	4.90	8.11
	Std. Deviation	10.25	2.98	1.56
	Range	37	14.7	8.5
	N	67	65	66

CFRD: Cystic Fibrosis Related Diabetes

Frequency of injections:

Frequency of injections in the CFRD group was fairly evenly spread between 1 and 5 injections a day, whereas the majority of type 1 diabetics injected 4 times a day. This is displayed graphically in Figures 3.1 and 3.2.

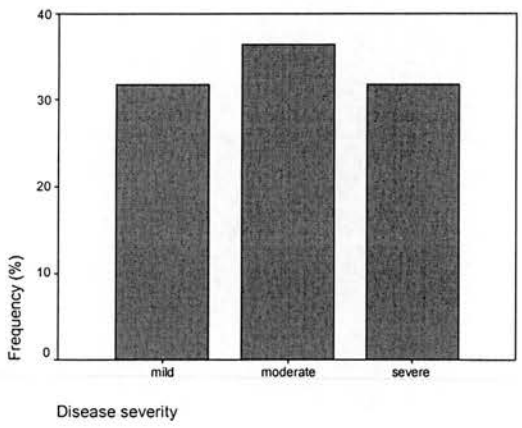
Figures 3.1 & 3.2. Frequency of injections



CF Disease severity:

The breakdown of the CF group by disease severity is shown in Figure 3.3. The sample consisted of seven individuals with mild disease (FEV1 percent predicted > 70%), 8 with moderate severity disease (FEV1 percent predicted 40-69%) and seven with severe disease (FEV1 percent predicted <40%).

Figure 3.3. Frequency of CF patients by disease severity



3.2 Hypotheses Testing

Descriptive/exploratory analysis relevant to each research question will be presented prior to analysis directly relating to the study hypotheses.

Hypothesis 1

Cystic Fibrosis patients will perceive fewer consequences and more control of their diabetes than Type 1 diabetic patients.

Descriptive information relating to the illness representations held by the Type 1 and CFRD groups is presented prior to analysis directly related to the hypothesis. In addition, associations between age, duration of diabetes, HbA1c levels and illness representations are explored.

Descriptive analysis: Illness Representations

The means and standard deviations of illness representations for both the Type 1 diabetic group and the cystic fibrosis related diabetic group are shown in Table 3.3. Examination of the mean scores for the different dimensions of illness representations shows that individuals diagnosed with Type 1 insulin dependent diabetes perceive their diabetes to be of chronic duration and they perceive high levels of personal control over their illness. These Type 1 diabetes patients also perceive high levels of illness coherence, suggesting that they have a good understanding of their illness, and scored moderately on perceived levels of treatment control and consequences of their illness. The Type 1 group were largely

positive in terms of their emotional response to their diabetes and did not perceive high levels of variation in their illness over time.

The illness representations held by the CFRD group were broadly similar. They too perceived their diabetes to be of chronic duration and perceived a good understanding of their illness. Similarly, they scored moderately on beliefs relating to levels of treatment control, however the mean score for the CFRD group was lower than the Type 1 group on perceptions of personal control. The cystic fibrosis group perceived moderate consequences of their diabetes and were relatively positive in terms of their emotional perceptions directly related to their diabetes. Again, in concordance with the Type 1 group, individuals with cystic fibrosis did not perceive high levels of variation in their illness over time.

Cause:

Twenty-eight percent of Type 1 diabetics gave inheritance as the primary cause for their diabetes followed by stress/worry (18%), germ/virus (18%) and chance/bad luck (13%). The majority of the Cystic Fibrosis related diabetes group detailed having CF as the primary cause of their diabetes (68%) followed by diet (9%), chance/bad luck (9%) and germ/virus (4.5%). A breakdown of the primary causes given is shown in Figures 3.4 and 3.5.

Table 3.3. Illness Representations for Type 1 Diabetic and Cystic Fibrosis related Diabetic patients

	diabetes diagnosis								
	type 1 diabetes			CFRD			Total		
	Mean	Std. Deviation	N	Mean	Std. Deviation	N	Mean	Std. Deviation	N
IPQ identity	2.27	1.95	45	1.68	1.70	22	2.07	1.88	67
timeline chronic	4.59	.47	45	4.39	.62	22	4.52	.52	67
consequences	3.09	.58	45	2.83	.67	22	3.01	.62	67
personal control	4.42	.53	45	3.92	.57	22	4.26	.58	67
treatment control	3.56	.54	45	3.45	.50	22	3.53	.52	67
illness coherence	4.02	.84	45	4.18	.52	22	4.07	.75	67
timeline cyclical	2.63	.85	45	2.76	.77	22	2.67	.82	67
emotional representations	2.51	.97	45	2.17	.75	22	2.40	.91	67

Figure 3.4. Primary cause of diabetes given by Cystic Fibrosis group

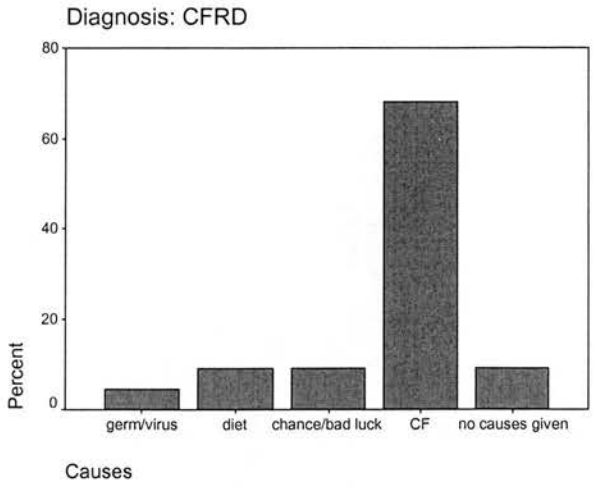
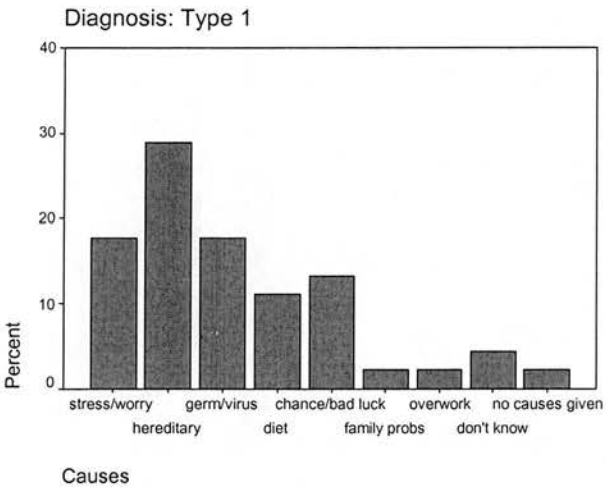


Figure 3.5. Primary cause of diabetes given by Type 1 Diabetic Group



Associations between age, clinical measures and Illness Representations:

There were no significant correlations between age, the clinical measures of duration of diabetes or HbA1c level, and any of the illness representation dimensions for either the Type 1 diabetic group or the CFRD group. Correlations were run with and without the outlier in the Type 1 diabetic group for the HbA1c measure and

again with and without the outlier in the CFRD group for duration since diagnosis. Results for each analysis were the same giving confidence in the findings reported.

Correlations between IPQ consequences, treatment control, personal control and CF disease severity:

Spearman's correlation analysis was carried out for the three different CF severity groups and the IPQ illness representation dimensions of consequences, treatment control and personal control. There were no significant correlations between CF disease severity and perceived consequences, treatment control or personal control. Correlations as given in Table 3.4.

Hypothesis 1 related analysis

The hypothesis that cystic fibrosis patients would perceive fewer consequences and more control of their diabetes than Type 1 diabetic patients was investigated by assessing the diabetes specific illness representations held by both groups using the diabetes specific version of the Illness Perceptions Questionnaire – Revised (IPQ-R) (Moss-Morris et al, 2002). One-way ANOVA analysis was performed to compare differences in scores between the Type 1 diabetics and the CFRD patients on the dimensions of perceived consequences, personal control and treatment control. See Table 3.3 for a breakdown of means and standard deviations. Alpha level was set at $p < .01$ to preserve the familywise alpha level (Cohen, 1992).

No significant differences between groups were found on the IPQ dimensions of perceived consequences or treatment control. (Table 3.5). Analysis of the observed power of these tests shows that power was calculated at .366 for consequences and

Table 3.4. Spearman's rho correlations for CF disease severity and the IPQ dimensions; consequences, treatment control and personal control.

			CF disease severity	IPQ consequences	IPQ personal control	IPQ treatment control
Spearman's rho	CF disease severity	Correlation Coefficient	1.000	-.108	.068	.311
		Sig. (2-tailed)	.	.631	.765	.158
		N	22	22	22	22
	IPQ consequences	Correlation Coefficient	-.108	1.000	-.079	-.062
		Sig. (2-tailed)	.631	.	.728	.784
		N	22	22	22	22
	IPQ personal control	Correlation Coefficient	.068	-.079	1.000	.340
		Sig. (2-tailed)	.765	.728	.	.122
		N	22	22	22	22
	IPQ treatment control	Correlation Coefficient	.311	-.062	.340	1.000
		Sig. (2-tailed)	.158	.784	.122	.
		N	22	22	22	22

.124 for treatment control. Despite non-significant results, a calculation of effect size (d) indicated that there was a medium effect of group on perceived consequences (d = .43) with Type 1 diabetic patients perceiving more consequences and a small effect of group on perceived treatment control (d = .21) (Lipsey, 1990) with the Type 1 group perceiving higher levels of treatment control.

A significant effect of group was found on the dimension of perceived personal control. Individuals with a diagnosis of Type 1 diabetes rated their perceived personal control to be significantly higher than individuals diagnosed with insulin dependent diabetes secondary to cystic fibrosis ($F(1,65) = 11.576$, $p = .001$). The estimate of effect size d indicated a large effect size (d = .93).

Table 3.5. One-way ANOVA: Differences between the Type 1 group and the CFRD group on the IPQ dimensions; consequences, treatment control and personal control

	Mean (sd)		F(1, 65)	Sig.
	Type 1	CFRD		
IPQ consequences	3.09 (.58)	2.83 (.67)	2.693	.106
IPQ treatment control	3.56 (.54)	3.45 (.50)	.646	.424
IPQ personal control	4.42 (.53)	3.92 (.57)	11.576	.001

Conclusions:

- The research hypothesis that cystic fibrosis patients would perceive fewer consequences and more control of their diabetes than the Type 1 group was not supported as no significant differences between groups were found on perceived levels of consequences or treatment control.

- Contrary to the hypothesis, results showed that cystic fibrosis related diabetes patients perceived significantly lower levels of personal control over their diabetes than individuals with Type 1 diabetes.
- There were no significant differences between CF patients with differing disease severity on dimensions of perceived consequences, treatment control or personal control of their diabetes.

Hypothesis 2

Low perceived control and high perceived consequences will be associated with higher levels of anxiety and depression in both groups.

Initial exploratory analysis was carried out to assess for levels of psychological well-being in both the Type 1 and CFRD groups and to look for any differences between groups on these measures. Associations between subscale scores on the different psychological well-being measures and between age, duration of diabetes, HbA1c levels and psychological well-being were explored. Exploratory analysis is presented prior to analysis related directly to the hypothesis.

Exploratory Analysis: Psychological Well-Being

Means and standard deviations of the psychological well-being scores for both the Type 1 and CFRD patient groups are presented in tables 3.6 and 3.7.

Table 3.6. Means and standard deviations for scores on the HADS

diabetes diagnosis		HADS total anx	HADS total dep	HADS total
type 1 diabetes	Mean	6.33	2.80	9.13
	Std. Deviation	4.09	2.62	5.90
	N	45	45	45
CFRD	Mean	4.73	2.32	7.05
	Std. Deviation	2.95	2.59	4.89
	N	22	22	22
Total	Mean	5.81	2.64	8.45
	Std. Deviation	3.81	2.60	5.64
	N	67	67	67

Table 3.7. Means and standard deviations for scores on the WBQ

diabetes diagnosis		WBQ anxiety score	WBQ depression score	WBQ energy score	WBQ well-being
type 1 diabetes	Mean	4.76	4.24	7.38	12.67
	Std. Deviation	3.45	2.92	2.55	3.55
	N	45	45	45	45
CFRD	Mean	3.18	3.36	6.95	13.95
	Std. Deviation	2.48	2.15	1.94	3.09
	N	22	22	22	22
Total	Mean	4.24	3.96	7.24	13.09
	Std. Deviation	3.23	2.71	2.36	3.44
	N	67	67	67	67

WBQ: Well-Being Questionnaire; CFRD: Cystic Fibrosis Related Diabetes

Hospital Anxiety and Depression Scale:

Mean scores were within the normal range on the Hospital Anxiety and Depression Scale (HADS). However, 31% of Type 1 patients and 14% of the CFRD sample reported a HADS anxiety score greater than 8 suggesting that they experienced levels of anxiety that were at least borderline for clinical significance. Similarly 7% of Type 1 and 9% of the cystic fibrosis sample scored above the cut off of 8 on the HADS depression scale again suggesting clinically significant levels of depression. For all but one patient (Type 1), a score above the clinical cut off on the depression measure, indicated a score above the clinical cut off on the anxiety measure.

Two-tailed t-tests showed that there were no significant differences between the individuals with Type 1 diabetes and those with cystic fibrosis related diabetes (CFRD) on either of the subscales measures of the HADS or on the HADS total score. See table 3.8.

The Well-being Questionnaire:

No clinical cut offs are published for the WBQ. One-sample t-tests found that mean scores for depression and positive well being did not differ significantly from normal adult Type 1 diabetic samples (data taken from Bradley, 1994) for either the study Type 1 or CFRD groups. There was a significant difference on the anxiety measure for the Type 1 group ($t=2.045$, $p < .001$) but not the CFRD group indicating that the Type 1 study sample reported significantly higher levels of anxiety symptoms than a normative comparison group.

Psychological well-being as measured by the WBQ again showed no statistically significant differences between groups on the measure of depression or on the measures of positive well-being (ie. energy and positive well-being). However, individuals with Type 1 diabetes reported significantly more anxiety symptoms than individuals with CFRD ($t = 2.491$, $p = .015$). These results are given in Table 3.9.

Table 3.8. Independent Samples t-test: Differences between Type 1 and CFRD groups on the HADS measure

	T	df	Sig (2-tailed)	95% Confidence Interval	
				Lower	Upper
HADS depression	1.642	65	.105	-.35	3.56
HADS anxiety	.466	55	.643	-.34	.55
HADS total	1.121	63	.266	-.16	.57

Table 3.9. Independent Samples t-test: Differences between Type 1 and CFRD groups on the WBQ measure

	t	df	Sig (2-tailed)	95% Confidence Interval	
				Lower	Upper
WBQ anxiety	2.491	62	.015	.094	.85
WBQ depression	1.255	65	.214	-.52	2.28
WBQ energy	.686	65	.495	-.81	1.65
WBQ well-being	-1.453	65	.151	-3.06	.48

Associations between clinical measures, age and psychological outcome

Neither duration of diabetes nor blood sugar level was significantly correlated with any psychological well-being measure for either the Type 1 or the CFRD groups. Age was positively correlated with the HADS depression score in the Type 1 group ($r=0.402$, $p= .01$), but not with other HADS or WBQ measures and there were no significant correlations between age and any of the psychological outcome measures for the cystic fibrosis related diabetes group.

Association between psychological measures and CF disease severity

Spearman's correlations were carried out to investigate whether there was any association between scores on the psychological well-being measures and level of Cystic Fibrosis disease severity in the CFRD group. The CF group was split into mild (n=7) moderate (n=8) and severe (n=7) disease severity categories. Correlations were performed for the subscales of the HADS and the HADS total score and similarly for the subscales of the WBQ.

There was a significant positive correlation between disease severity and the HADS depression score (rho = .611, p = .009, two-tailed) but no significant correlation between disease severity and either HADS anxiety, HAD total score or any of the WBQ subscales (see tables 3.10 & 3.11).

Table 3.10. Spearman's rho correlations for CF disease severity and HADS scores.

			CF disease severity	HADS anxiety	HADS depression	HADS total
Spearman's rho	CF disease severity	Correlation Coefficient	1.000	.091	.611**	.439*
		Sig. (2-tailed)	.	.689	.009	.046
		N	22	22	17	21
	HADS anxiety	Correlation Coefficient	.091	1.000	.267	.858**
		Sig. (2-tailed)	.689	.	.300	.000
		N	22	22	17	21
	HADS depression	Correlation Coefficient	.611**	.267	1.000	.664**
		Sig. (2-tailed)	.009	.300	.	.004
		N	17	17	17	17
	HADS total	Correlation Coefficient	.439*	.858**	.664**	1.000
		Sig. (2-tailed)	.046	.000	.004	.
		N	21	21	17	21

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

Table 3.11. Spearman's rho correlations for CF disease severity and WBQ scores

			CF disease severity	WBQ depression	WBQ anxiety	WBQ energy	WBQ well-being
Spearman's rho	CF disease severity	Correlation Coefficient	1.000	.277	.092	-.281	-.299
		Sig. (2-tailed)	.	.212	.684	.205	.176
		N	22	22	22	22	22
	WBQ depression	Correlation Coefficient	.277	1.000	.719**)	-.640**)	-.772**)
		Sig. (2-tailed)	.212	.	.000	.001	.000
		N	22	22	22	22	22
	WBQ anxiety	Correlation Coefficient	.092	.719**)	1.000	-.451*	-.587**)
		Sig. (2-tailed)	.684	.000	.	.035	.004
		N	22	22	22	22	22
	WBQ energy	Correlation Coefficient	-.281	-.640**)	-.451*	1.000	.707**)
		Sig. (2-tailed)	.205	.001	.035	.	.000
		N	22	22	22	22	22
	WBQ well-being	Correlation Coefficient	-.299	-.772**)	-.587**)	.707**)	1.000
		Sig. (2-tailed)	.176	.000	.004	.000	.
		N	22	22	22	22	22

**). Correlation is significant at the 0.01 level (2-tailed).

*). Correlation is significant at the 0.05 level (2-tailed).

Hypothesis 2 related analysis:

Pearson's correlation analysis was carried out to test the hypothesis that low perceived control and high perceived consequences would be associated with higher levels of anxiety and depression in both groups. Analysis was carried out independently for the Type 1 diabetic group and the CFRD groups with the alpha level set at $p < .01$ in order to reduce the chances of making Type 1 errors due to multiple comparisons (Cohen, 1992).

Type 1 diabetes:

Consequences:

Greater perceived consequences were associated with the HADS depression ($r = .442$, $p = .004$) and total scores ($r = .456$, $p = .002$) but not HADS anxiety (table 3.12). Similarly, associations approaching significance were found between perceived consequences and the WBQ measure of depression ($r = .359$, $p = .015$) but not WBQ anxiety (table 3.13). Thus higher levels of perceived consequences amongst the Type 1 sample were associated with higher scores on measures of depression. In the case of correlations r was taken as the effect size as recommended by Cohen (1992). Correlations ranged from .36 to .46 indicating medium to large effect sizes (Cohen, 1992).

Control:

A negative correlation approaching significance was found between the treatment control dimension and the HADS measure of depression ($r = -.389$, $p = .013$) but not anxiety (table 3.12). Similarly, perceived treatment control approached a significant negative correlation with WBQ depression ($r = -.355$, $p = .017$) but not anxiety (table

3.13). Thus, patients' beliefs in higher levels of treatment control were associated with lower levels of depressive symptomatology. Correlations were indicative of medium effect sizes (Cohen, 1992).

Personal control was not significantly correlated with either the anxiety or depression measures of the Hospital Anxiety and Depression Scale (HADS) or the Well-Being Questionnaire (WBQ).

Cystic Fibrosis Related Diabetes

No significant correlations were found, for the CFRD group, between illness representations and anxiety and depression measures on the HADS or the WBQ at the $p < .01$ significance level (tables 3.14 & 3.15). The lack of significant correlations could be a function of the small sample size and consequently the reduced power of this test. However, examination of the r values found that correlation coefficients ranged between .025 and .332 on the HADS measure and between .002 and .318 on the WBQ suggesting instead, that effect sizes were small and non-significant findings in the CFRD group were not simply a function of the smaller sample size.

Table 3.12. Pearson's Correlation Analysis: Illness Representations; consequences, treatment control and personal control and the subscales of the HADS for the Type 1 group.

		HADS anxiety	HADS depression	HADS total	IPQ consequences	IPQ personal control	IPQ treatment control
HADS anxiety	Pearson Correlation	1	.465**)	.916**)	.348*	.355*	-.121
	Sig. (2-tailed)	.	.003	.000	.022	.020	.441
	N	43	39	43	43	43	43
HADS depression	Pearson Correlation	.465**)	1	.731**)	.442**)	-.082	-.389*
	Sig. (2-tailed)	.003	.	.000	.004	.615	.013
	N	39	40	40	40	40	40
HADS total	Pearson Correlation	.916**)	.731**)	1	.456**)	.172	-.195
	Sig. (2-tailed)	.000	.000	.	.002	.264	.206
	N	43	40	44	44	44	44
IPQ consequences	Pearson Correlation	.348*	.442**)	.456**)	1	-.023	-.048
	Sig. (2-tailed)	.022	.004	.002	.	.881	.756
	N	43	40	44	45	45	45
IPQ personal control	Pearson Correlation	.355*	-.082	.172	-.023	1	-.129
	Sig. (2-tailed)	.020	.615	.264	.881	.	.399
	N	43	40	44	45	45	45
IPQ treatment control	Pearson Correlation	-.121	-.389*	-.195	-.048	-.129	1
	Sig. (2-tailed)	.441	.013	.206	.756	.399	.
	N	43	40	44	45	45	45

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

Table 3.13. Pearson's Correlation Analysis: Illness Representations; consequences, treatment control and personal control and the anxiety and depression subscales of the WBQ for the Type 1 group.

		WBQ anxiety	WBQ depression	IPQ consequences	IPQ personal control	IPQ treatment control
WBQ anxiety	Pearson Correlation	1	.635**	.330*	.087	-.235
	Sig. (2-tailed)	.	.000	.027	.568	.120
	N	45	45	45	45	45
WBQ depression	Pearson Correlation	.635**	1	.359*	-.097	-.355*
	Sig. (2-tailed)	.000	.	.015	.527	.017
	N	45	45	45	45	45
IPQ consequences	Pearson Correlation	.330*	.359*	1	-.023	-.048
	Sig. (2-tailed)	.027	.015	.	.881	.756
	N	45	45	45	45	45
IPQ personal control	Pearson Correlation	.087	-.097	-.023	1	-.129
	Sig. (2-tailed)	.568	.527	.881	.	.399
	N	45	45	45	45	45
IPQ treatment control	Pearson Correlation	-.235	-.355*	-.048	-.129	1
	Sig. (2-tailed)	.120	.017	.756	.399	.
	N	45	45	45	45	45

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

Table 3.14. Pearson's Correlation Analysis: Illness Representations; consequences, treatment control and personal control and the subscales of the HADS for the CFRD group.

		HADS anxiety	HADS depression	HADS total	IPQ consequences	IPQ personal control	IPQ treatment control
HADS anxiety	Pearson Correlation	1	.380	.883**	.174	.025	.199
	Sig. (2-tailed)	.	.132	.000	.439	.912	.375
	N	22	17	21	22	22	22
HADS depression	Pearson Correlation	.380	1	.670**	-.181	.332	.016
	Sig. (2-tailed)	.132	.	.003	.488	.193	.951
	N	17	17	17	17	17	17
HADS total	Pearson Correlation	.883**	.670**	1	.064	-.015	.070
	Sig. (2-tailed)	.000	.003	.	.784	.950	.763
	N	21	17	21	21	21	21
IPQ consequences	Pearson Correlation	.174	-.181	.064	1	-.105	-.076
	Sig. (2-tailed)	.439	.488	.784	.	.642	.735
	N	22	17	21	22	22	22
IPQ personal control	Pearson Correlation	.025	.332	-.015	-.105	1	.285
	Sig. (2-tailed)	.912	.193	.950	.642	.	.199
	N	22	17	21	22	22	22
IPQ treatment control	Pearson Correlation	.199	.016	.070	-.076	.285	1
	Sig. (2-tailed)	.375	.951	.763	.735	.199	.
	N	22	17	21	22	22	22

**. Correlation is significant at the 0.01 level (2-tailed).

Table 3.15. Pearson's Correlation Analysis: Illness Representations; consequences, treatment control and personal control and the anxiety and depression subscales of the WBQ for the CFRD group.

		WBQ depression	WBQ anxiety	IPQ consequences	IPQ personal control	IPQ treatment control
WBQ depression	Pearson Correlation	1	.765**	.083	-.002	.318
	Sig. (2-tailed)	.	.000	.713	.992	.149
	N	22	22	22	22	22
WBQ anxiety	Pearson Correlation	.765**	1	.135	.068	.194
	Sig. (2-tailed)	.000	.	.548	.765	.387
	N	22	22	22	22	22
IPQ consequences	Pearson Correlation	.083	.135	1	-.105	-.076
	Sig. (2-tailed)	.713	.548	.	.642	.735
	N	22	22	22	22	22
IPQ personal control	Pearson Correlation	-.002	.068	-.105	1	.285
	Sig. (2-tailed)	.992	.765	.642	.	.199
	N	22	22	22	22	22
IPQ treatment control	Pearson Correlation	.318	.194	-.076	.285	1
	Sig. (2-tailed)	.149	.387	.735	.199	.
	N	22	22	22	22	22

**. Correlation is significant at the 0.01 level (2-tailed).

Predicting levels of anxiety and depression:

Stepwise multiple regression analysis was used to assess the role played by illness representations in predicting levels of anxiety and depression. All illness representation dimensions, except cause, as this was a categorical variable, were entered into the analysis. All eight other illness representation dimensions; identity, timeline acute/chronic, timeline cyclical, consequences, treatment control, personal control, illness coherence and emotional representations were available to the model. The Well-Being Questionnaire subscales of anxiety and depression were used as dependent variables as these had similarly been used elsewhere in the literature. When regression analysis was performed for the CFRD group, no variables were entered into the model therefore results given below relate to the Type 1 diabetes group.

Regression analysis found depression in the Type 1 group to be significantly predicted by both emotional representations and treatment control, and anxiety to be predicted by emotional representations and beliefs in a more acute time course of the illness (Table 3.16). The analysis was repeated but was subsequently only interested in the role played by cognitive illness representations in the prediction of levels of anxiety and depression. The emotional representations dimension was therefore removed and only the cognitive illness representation dimensions entered into the equation. Regression analysis subsequently found that depression was predicted by consequences and treatment control and anxiety was predicted by both beliefs in an acute and cyclical time course of the illness (Table 3.17).

Table 3.16. Regression Analysis to predict WBQ anxiety and depression from illness representations

Dependent Variable	Model	R squared	Adjusted R squared	Standardised Beta coefficient	t	Sig
WBQ depression	1. IPQ Emotional Representations	.187	.168	.433	3.148	.003
	2. IPQ Emotional Representations			.395	2.999	.005
	IPQ treatment control	.280	.246	-.307	2.331	.025
WBQ anxiety	1. IPQ Emotional Representations	.390	.376	.625	5.246	.000
	2. IPQ Emotional Representations	.390	.376	.604	5.313	.000
	IPQ timeline acute/chronic	.461	.435	-.267	2.349	.024

Table 3.17. Regression analysis to predict WBQ anxiety and depression from cognitive illness representations alone

Dependent Variable	Model	R Squared	Adjusted R Squared	Standardised Beta Coefficient	t	Sig
WBQ depression	1. IPQ consequences	.129	.109	.359	2.522	.015
	2. IPQ consequences			.343	2.552	.014
	IPQ treatment control	.244	.208	-.339	2.523	.016
WBQ anxiety	1. IPQ timeline cyclical	.137	.115	.370	2.520	.016
	2. IPQ timeline cyclical			.429	3.154	.003
	IPQ timeline chronic	.294	.257	-.400	2.941	.005

Conclusions:

- Higher perceived consequences and lower perceived treatment control were significantly associated with levels of depression, but not anxiety, in the Type 1 diabetic group.
- This study did not show significant correlations between illness representations and psychological outcome in the Cystic Fibrosis related diabetic group.
- Illness representations other than consequences and control were predictive of levels of anxiety in the Type 1 group; beliefs in a more acute and cyclical time course of illness were predictive of levels of anxiety in the Type 1 group.
- Emotional representations were predictive of both anxiety and depression in the Type 1 group.

Hypothesis 3

Differences will exist between staff and patients' illness representations on dimensions of consequences and control.

Descriptive analysis – Illness Representations

A total of 17 staff completed and returned the questionnaire. This sample consisted of 8 staff nurses, the ward charge nurse and 8 members of the multi-disciplinary cystic fibrosis team. Means and standard deviations of the illness representation dimensions of consequences, personal control and treatment control for both the CFRD group and the staff group are given in table 3.18. Examination of the mean scores of these dimensions shows that staff perceived moderate consequences for their patients due to their diabetes and moderate levels of treatment control. In addition, staff perceived that their cystic fibrosis patients had relatively high levels of personal control over their diabetes.

Hypothesis 3 related analysis

Levene's test for equality of variance showed that there was heterogeneity of variance therefore t-test analysis, which accounted for this violation, was performed to test the hypothesis that differences would exist between staff and patients illness representations on dimensions of consequences and control (Table 3.19). Two-tailed t-tests compared differences in scores between the CFRD group and the staff group on the illness representation dimensions of consequences, treatment control and personal control. There was a significant difference between the groups on the consequences dimension ($t = -4.602$, $p < .001$). Staff believed that their patients' diabetes had significantly more consequences for the patient than the patients

themselves did. There were no significant differences between the staff and patient groups on perceived levels of treatment or personal control.

Conclusions:

- Staff perceived significantly greater consequences of a diagnosis of diabetes in their patients than the patients themselves did.
- Statistically significant differences did not exist between the staff and patient groups on perceived levels of treatment or personal control.
- The hypothesis that difference will exist between staff and patients illness representations is partially supported.

Table 3.18. Illness Representation for Cystic Fibrosis related Diabetes patients and Staff

	Diabetes diagnosis					
	CFRD			Staff		
	Mean	Std. Deviation	N	Mean	Std. Deviation	N
Consequences	2.83	.67	22	3.57	.30	17
Personal control	3.92	.57	22	4.10	.42	17
Treatment control	3.45	.50	22	3.47	.69	17

Table 3.19. Independent Sample t-test: Differences between CFRD and Staff groups on IPQ consequences, treatment control and personal control

	T	df	Sig (2-tailed)	95% confidence interval	
				Lower	Upper
IPQ consequences	-4.602	30.724	.000	-6.368	-2.456
IPQ personal control	-1.093	36.979	.281	-2.975	.890
IPQ treatment control	-.081	28.056	.936	-2.108	1.948

4. Discussion

Overview

The role of illness representations in the psychological well-being of patients with insulin dependent diabetes was investigated in two different patient groups; patients with Type 1 diabetes and patients with Cystic Fibrosis related Diabetes. Forty five patients with Type 1 and 22 patients with CFRD completed measures relating to perceived illness representations and psychological well-being. The aims of the present study were to address three specific research questions: (1) to compare the illness representations held by patients with Type 1 diabetes, with those held by patients with Cystic Fibrosis related diabetes and to determine whether differences in representations of consequences and control existed between groups (2) to investigate the relationship between illness representations and psychological adjustment in patients with insulin dependent diabetes and (3) to compare patients' perceptions of illness with the perceptions of illness held by the hospital based, multi-disciplinary team involved in their care. Results of the study are discussed in this section and findings are compared with previous research reported in the literature. Methodological limitations of the present study are considered. Clinical implications of the results for the psychosocial care of patients with Type 1 and Cystic Fibrosis related diabetes are discussed. Finally conclusions are drawn and directions for future research are identified.

4.1 Summary of Main Findings

Q1: Illness Representations of Diabetes

The Self-Regulatory model (Leventhal, Meyer & Nerenz, 1984) provides researchers and clinicians with a framework that attempts to explain the variation in adjustment and outcome to illness, by identifying the ways in which patients cognitively and emotionally respond to the threat posed by illness. Leventhal's self-regulatory model proposes that in response to illness and other health threats, two parallel response processes are activated. People develop both cognitive and emotional responses to the threat of ill health. Patient's cognitive representations of illness are assessed along a number of dimensions including identity (the label given to the illness and its symptoms) cause (the perceived cause of the illness), timeline (the patient's beliefs about the likely timeline of the illness ie is it acute/chronic, unpredictable), consequences (the impact of the illness in physical and emotional terms), and controllability (beliefs about how well the illness can be managed or cured). In addition the patient's emotional response to illness is assessed.

The present study employed this framework to investigate the beliefs held by patients about their illness, using the revised Illness Perceptions Questionnaire (Moss-Morris et al, 2002). This study used a version of the questionnaire specifically developed for use with patients with diabetes.

Type 1 Diabetes

Patients in the Type 1 diabetic group obtained scores on the different dimensions of illness representations similar to those reported elsewhere, using the same measure, with an adolescent Type 1 sample (Law et al, 2002). On the whole, the sample

perceived their diabetes to be of chronic duration, they scored highly on the illness coherence dimension and perceived high levels of personal control over their illness. The Type 1 diabetic patients perceived moderate levels of treatment control over their diabetes and moderate consequences of their illness. The consequences dimension of the questionnaire used in this study consisted of questions relating to beliefs about the seriousness of the illness, the impact of having diabetes on the patient's life, financial consequences and the effect having diabetes has on relationships with others. As there currently is no cure for diabetes, patients correctly identified their illness as having a chronic course. High levels of illness coherence reflected a sense that patients had a good understanding of their illness perhaps indicating that patients are well informed about their disease. Beliefs regarding treatment control are likely to reflect an informed and realistic appraisal of their illness. Treatment for Type 1 diabetes can help patients to manage their condition and is important in order to prevent the onset of complications, but ultimately it is not a cure. Treatment for this condition does have its limitations and this appears to be reflected by the perceptions of treatment control held by this patient sample.

Cystic Fibrosis related Diabetes

Investigation into the role of illness representations in the adjustment and outcome of diabetes has a growing literature base, however this framework has not previously been used to understand adaptation to diabetes in patients with cystic fibrosis. Scores obtained on the illness representation dimensions for the cystic fibrosis related diabetes sample in the current study showed largely similar results to those found in the Type 1 group. These findings again appear to reflect the realistic factors

associated with diabetes and suggest that the cystic fibrosis sample, like both the adolescent and adult Type 1 groups, are well informed about their disease.

Differences between patient groups on perceptions of consequences and control

Consequences and Treatment Control

Findings from the present study show that there were no statistically significant differences between the cystic fibrosis related diabetes group and the Type 1 diabetes group on the illness representation dimensions of consequences or treatment control. It was predicted that patients with CFRD would perceive more control and fewer consequences of their diabetes than the Type 1 group. The fact that no significant differences between groups were found on these dimensions perhaps emphasises that although patients with a pre-existing illness do have experience of coping with the limitations and management of a chronic condition, the increased burden of illness consequent of a secondary diagnosis should not be ignored. However, it is possible that there was insufficient statistical power in the present study to detect a difference between groups that does exist in the population. A calculation of effect size suggests that there was a medium effect of group, with Type 1 diabetic patients rating the perceived consequences of diabetes higher than the CFRD group. A medium effect size could be interpreted as clinically relevant and may reflect denial, minimisation or a simple lack of awareness of the consequences of diabetes in the Cystic Fibrosis sample.

Personal Control

It was initially predicted that patients with CFRD would perceive greater personal control over their diabetes than Type 1 diabetic patients. However, participants in the

Type 1 diabetic group perceived significantly more personal control over their diabetes than those with cystic fibrosis related diabetes. This finding was in opposition to that hypothesised. An estimate of effect size indicated a large effect of group suggesting that this is a clinically relevant finding and therefore warrants further investigation.

Illness representation dimensions are likely to be inter-related and it is difficult to understand a single attribute without an understanding of how it may be implicitly or explicitly linked to others (Hampson, 1997; Leventhal et al, 1997). Reference to the patients' perceived causes of diabetes may give us some insight into this unexpected finding regarding personal control.

Whereas the Type 1 group gave a wide range of causes for the onset of their diabetes, 68% of the CF sample detailed having pre-existing cystic fibrosis as the primary cause of their diabetes. Other than having CF, only 3 other causes were given by the CF group, namely, chance/badluck, diet and germ/virus. Infections and dietary control are factors that play major roles in the course and management of Cystic Fibrosis and the decision to start insulin in patients with cystic fibrosis related diabetes may be a result of declining lung function or detrimental decreases in body weight (Lanng et al, 1994b). An abnormal glucose tolerance test alone, will not necessarily result in the need for insulin treatment in CF patients, thus the CF patients who attributed their diabetes to diet or germ/virus, may therefore be indirectly attributing the cause of their diabetes to the course of their cystic fibrosis. A closer examination of the circumstances surrounding the start of insulin therapy in patients was beyond the scope of the present study. However, such investigation may uncover a temporal

relationship between an exacerbation of the patient's CF disease, or weight loss and the commencement of insulin that could explain the causes given.

The majority of patients with CFRD correctly identified the cause of their diabetes as being a result of the progression of their cystic fibrosis. Although management of CF is aimed at slowing the progression of the disease, patients' conditions will deteriorate and they do face a foreshortened lifespan. For some, the onset of cystic fibrosis related diabetes is indicative of their condition 'going downhill' (Lowton & Gabe, 2003). The finding that the CFRD groups perceived less control over their diabetes than the Type 1 group may suggest that CF patients perceive their diabetes as a largely uncontrollable consequence of the progression of their cystic fibrosis whereas the Type 1 group have a distinct disease which they may be more likely to perceive as controllable.

In addition challenges occur due to the complications of the cystic fibrosis disease as patients with a secondary diagnosis of diabetes are often malnourished, requiring overnight enteral tube feeding resulting in adjusted insulin regimes (Wilson et al, 2000). Dietary intake can vary greatly from day to day in CF patients because of pulmonary and gastrointestinal disease therefore a flexible regimen is usually required. In addition patients with CFRD may become tremendously insulin resistant when they are acutely ill and may need considerably larger insulin doses than usual (Moran, 2002). In light of these factors it may be understandable that individuals with cystic fibrosis related diabetes perceive lower levels of personal control over their diabetes than those individuals with type 1 diabetes; their treatment regimen is less well defined and the additional complications due to their cystic fibrosis disease

impact significantly on their diabetic control. Clinically it is therefore important that CFRD is managed in joint clinics with specialists from both the cystic fibrosis and diabetic services working in collaboration.

Q2: The association between consequences/control and anxiety and depression

The self-regulatory model has been investigated in terms of the role of illness representations in predicting adaptive outcome. Studies focussing on a variety of different illnesses have provided evidence that perceived consequences and control of illness are important factors influencing medical and psychological outcome (Heijmans, 1998; Jopson & Moss-Morris, 2003; Scharloo et al, 1998). In the literature investigating the role of illness representations and their association with psychological well-being in diabetes, perceived control has been found to be a significant predictor of positive perceptions of quality of life (Watkins et al, 2000; Law et al, 2002), and perceived consequences have been found to be significant predictors of anxiety and depression (Edgar & Skinner, 2003; Law et al, 2002; Skinner et al, 2000).

The present study aimed to investigate the relationship between diabetes illness representations and psychological well-being in both a Type 1 diabetic sample and a cystic fibrosis related diabetic sample. To the author's knowledge, this relationship had never previously been investigated in a CFRD sample.

The present study added further evidence to the literature in support of the association between illness representations and psychological outcome measures. However when

these relationships were examined distinctly for each diabetic group the relationships between these factors varied depending on the underlying illness.

Type 1 diabetes

For the Type 1 group, in line with previous research, fewer perceived consequences and greater perceived levels of control were associated with lower levels of depression, however they were not significantly correlated with levels of anxiety. The contribution of the consequences and treatment control measures in the prediction of depression was underlined in multiple regression analysis, which found that a combination of these two dimensions accounted for a significant amount of the variance in levels of depression amongst the Type 1 patient sample. Multiple regression analysis suggested that cognitive illness representations other than consequences and treatment control were predictive of levels of anxiety. Perceived daily variability of diabetes as well as beliefs that diabetes was not a chronic condition were predictive of levels of anxiety. When emotional representations, ie the patient's direct emotional response to their diabetes, was added to the model, it was found to be the greatest predictor of levels of both anxiety and depression in the Type 1 sample.

Cystic Fibrosis related Diabetes

A different pattern of relationships was found within the CFRD sample. Unlike the Type 1 sample, neither perceived consequences nor control of diabetes was associated with anxiety or depression. Examination of the effect sizes would suggest that this finding was not just an artefact of the smaller sample size.

The contribution of illness representations other than consequences and control

In the CFRD group, although results were not significant, examination of the correlation coefficients showed that the timeline cyclical dimension was associated with poorer psychological well-being. Patients who perceived the course of their diabetes to vary from day-to-day, therefore perhaps feeling that their diabetes was unpredictable, were more likely to score negatively on measures of psychological well-being. Interestingly there appeared to be no relationship between the direct emotional response to diabetes and measures of psychological well-being in this group. It is difficult to draw any conclusive reasons for this from the data however this may be a function of the CF patients failing to draw a clear distinction between their diabetes and the CF disease or it may reflect the fairly good overall adjustment of the cystic fibrosis sample.

Q3: The role of social context

It has been recommended that the self-regulatory framework be extended into the social context (Law, 2002; Leventhal et al, 1997). Leventhal's model acknowledges the role of social factors in the appraisal of illness, yet despite this, there has been relatively little research focussing on the impact of the social context on the appraisal and outcome of illness. Studies that have investigated the association between the respective beliefs held by patients, their family members or health care providers and psychological outcome have shown that dissimilarity in views of illness held by different individuals can contribute to coping and adaptive outcome (Heijamns et al, 1999;Heijmans et al, 2001 Law, 2002, Richards et al, 2004; Salewski, 2003). It has further been suggested that differences between the perceptions of illness held by patients and their health care providers about the stressors faced by patients with

chronic illness may lead to misunderstandings and disrupt effective communication (Heijmans et al, 2001). The present study aimed to investigate if differences in illness representations existed between patients with CFRD and the health care staff involved with their care.

The findings of the present study supported the results obtained by Heijmans et al (2001) that patients and health care providers can diverge in the way they think about illness. The staff group perceived significantly more consequences of diabetes for their patients than the patients themselves did, however, beliefs relating to control held by patients and staff were similar.

This is an interesting finding as anecdotally staff tended to assume that the secondary diagnosis would bare little additional impact on the patient. A closer examination of the factors which make up the consequences dimension of the IPQ-R may give us some insight into the nature of the divergence in beliefs between the two groups. Examination shows that 100% of staff respondents agreed with the statements that the patients' diabetes is a serious condition and that it had major consequences on the individuals' lives. Eighty two percent and 41% of patient participants agreed with these statements respectively. Again, this highlights that CFRD patients are perhaps minimising or are simply ill-informed about the consequences of their diabetes. When asked about their views on the impact of their diabetes on relationships with others, 22% of the CFRD patient group agreed that their diabetes caused difficulties for those close to them, whereas 41% of staff perceived that the patients' diabetes would cause difficulties in this way. However, both the staff and patient groups had similar views that diabetes did not incur serious financial consequences for the patient

The discrepancy in perceptions between staff and patients regarding the seriousness of a diagnosis of diabetes in CF patients may reflect on one hand, as has been suggested elsewhere (Heijmans et al, 2001), that perceptions of illness held by staff are more congruent with medical knowledge than the patients' subjective experience. Alternatively, this may reflect a lack of information in the patient group or, that to some extent patients deny or minimize the seriousness of their condition in an effort to maintain a positive attitude to their health. Illness beliefs regarding control did not differ between the two groups, which would suggest that both groups recognised the limitations to control diabetes in this patient population. Heijmans' (2001) proposal that diverging views between patients and health care providers may lead to misunderstandings and disrupt communication highlights the importance of recognising and acknowledging the beliefs held by both groups in the continuing care of individuals with chronic illness. The current study supports Heijmans findings that incongruent beliefs do exist although this study did not directly investigate the impact of similar/dissimilar view on psychological, behavioural or medical outcome. This may be an avenue to explore in future research.

4.2 Methodological Limitations

In interpreting these findings we must consider limitations to the present study.

Sample Size

The limited number of participants recruited to this study left the study vulnerable to the effects of low statistical power. To control for the effects of conducting multiple tests of statistical significance the alpha level ie. the probability of detecting an effect when in fact none exists, was set at the more stringent value of 0.01. This more

conservative level of statistical probability meant that the sample sizes in this study were relatively small.

Sample Representativeness

Response rates of 71% and 47% were achieved in the CFRD group and the Type 1 group respectively. Considering that research using postal questionnaires often has around a one-third non-response rate (Dillman, 2000) the rate achieved for the CFRD group was consistent with that expected, however, the response rate in the Type 1 group was relatively low. This may be a function of the closer contact the researcher had with the CFRD group and therefore their increased willingness to participate. The presence of non-responders immediately introduces a bias into the results as non-responders may differ from responders on a number of factors including interest, motivation, psychological state or disease state.

The present study did not have access to information to assess whether or not responders differed significantly from non-responders on these factors therefore the generalizability of the findings should be interpreted with caution. Results regarding the association between illness representations and psychological well-being replicate other studies that have found similar association between these measures in both adolescent and adult, Type 1 and Type 2 diabetic populations. However, these associations have not previously been investigated in a CFRD population therefore replication of these findings is required before confidence in the conclusions can be assured.

Study Design

The cross-sectional nature of this study does not allow causal inferences to be made. Although correlational relationships allow us to establish that two factors covary they do not allow us to establish the temporal or causal relationships between them. Due to the time-scale limitations of this study a prospective study was not feasible. However without a prospective design, the study is unable to capture the dynamic interaction between illness representations and psychological outcome or the recursive nature of the self-regulatory model.

Recent studies have questioned support for the self-regulatory model in its ability to predict coping and self-management behaviours in diabetic patients although they have supported the role of illness representations in the psychological presentation of these patients (Edgar & Skinner, 2003; Law et al, 2002). The current study is unable to make conclusive statements either in support or opposition to the theoretical framework of the Self-Regulatory Model as it did not look at the mediating role of coping in psychological adjustment nor did it investigate self-management behaviours. This may be an interesting area of investigation for future research.

Critique of Measures Used

The Hospital Anxiety and Depression Scale (HADS)

The HADS scale is a measure of anxiety and depression used widely with medical patients both clinically and in research. The scale provides a brief measure of anxiety and depression which may be useful for screening and monitoring psychological distress. The HADS may be the most useful measure for monitoring levels of psychological distress in CFRD patients, as it avoids items relating to somatic

manifestations of depression and anxiety which could lead to elevated scores in populations of patients suffering from a medical condition. No disease specific measure of anxiety or depression is currently available for CFRD patients. The HADS measure is currently being used for routine monitoring with all CF patients in the service in Edinburgh.

The Well-Being Questionnaire (WBQ)

The WBQ is a measure that was developed specifically for use with diabetic patients and has been used in previous research interested in the association between illness representations and psychological well-being. Although the scale has been shown to have good validity and reliability with a diabetic population, its validity with a CFRD population may be questionable. This is perhaps highlighted by the variable association found between measures on the HAD scale and measures on the WBQ scale for the CFRD group. As the WBQ was developed as a disease specific measure, a more general measure of anxiety and depression, such as the HADS, may be more a reliable measure of psychological outcome in the CFRD population. Either the WBQ or the HADS may be appropriate for routine psychological monitoring with the Type 1 diabetic group.

The Illness Representation Questionnaire-Revised (IPQ-R)

In this study the diabetes, disease-specific, version of the IPQ-R was used. This questionnaire referred explicitly to the patient's diabetes, which was important in order to address the research questions. As the CFRD group had a pre-existing chronic illness, the use of this questionnaire enabled us to be fairly confident that the participants were answering the questions with reference to their diabetes opposed to

their CF disease as a whole. However, the results of this study would suggest that CFRD patients largely perceive their diabetes as a consequence or progression of the CF disease and therefore this may, in fact, be a fairly arbitrary distinction for these patients.

To the author's knowledge, the role of illness representations in cystic fibrosis have not previously been investigated, therefore further research is required to validate the use of this scale with this clinical population. However previous studies have shown this measure to have good reliability (Moss-Morris et al, 2002) and it has been used elsewhere with diabetic populations (Law, 2002). The present study used this measure in order to allow comparison with previous research.

Use of a questionnaire to assess illness representations does not allow the study to access patient self-generated illness representations. It could be argued that this imposes a restriction on patients and therefore by design may be excluding key dimensions that patients themselves view as important. In his original work, Leventhal conducted interviews with patients, which he argued allowed them to generate their own beliefs rather than having a pre-determined researcher oriented framework imposed upon them. However, ensuing research has consistently provided support for the dimensions subsequently included in the IPQ and therefore this allows us to take some confidence in the relevance of the dimensions used.

4.3 Discussion of Clinical Implications

The findings emphasise that attention to the psychological factors involved in adapting to chronic illness must not be ignored and that routine monitoring of patients' psychological as well as their physical state should be encouraged.

Incidence of Anxiety and Depression

Findings from the current study show that the incidence of psychological distress, in concordance with previous literature, is relatively high in the Type 1 diabetic sample (Anderson et al, 2001a; Jacobson, 1996 Jacobson et al, 2002; Lustman, 1988; Peyrot & Rubin, 1997). Thirty-one percent of the sample experienced levels of anxiety that were at least borderline for clinical significance. However, the reportedly high levels of depression in Type 1 diabetic samples was not supported by the current study as only 7% of the sample scored above the cut off indicating a clinically significant level of depression. This unexpectedly low figure may be a function of the representativeness of the study sample; perhaps patients who were experiencing more depressive symptomatology were less likely to participate. As levels of psychological distress are not currently routinely monitored within the diabetic clinic, there was no way of accessing this information to corroborate or reject this theory.

Within the cystic fibrosis related diabetic sample 14% scored above the cut-off level indicating levels of anxiety that were at least borderline for clinical significance and 9% scored above the cut-off indicating similar levels of depression. This is considerably lower than the 20-25% prevalence detailed for patients with a chronic medical condition and supports previous findings that have provided evidence of

relatively good psychological adaptation in adult CF populations (Anderson et al, 2001b; Blau et al, 2003; Cowen et al, 1984).

An important clinical point to note, is that where patients, in either group, experienced levels of depression that were within the clinical range they were also likely to experience higher levels of anxiety. Comorbidity in depression is widely recognised and it is often accompanied by concurrent or recent anxiety (Hammen, 2001). The implication of this is that comorbidity of depression can imply worse functioning (Lewinsohn, Rohde & Seeley, 1995) and in the context of chronic disease, this may have significant behavioural, medical and psychological implications.

Theoretical models in clinical health psychology are only of value to the extent that they can guide assessment and intervention (Law, 2002). It is therefore important in conducting research that the clinical implications of the findings are considered. In assessing the clinical implications of the present study we will consider the two patient groups independently.

Type 1 Diabetes

The findings concerning the Type 1 diabetic group supported previous research that had found an association between illness representations held by patients and their psychological well-being. In particular, cognitive representations concerning perceptions of consequences and control were associated with patients' levels of psychological distress. As these results replicated findings from earlier studies, this association would appear to be a fairly robust, suggesting that where appropriate, interventions should be targeted at optimising patients' perceptions of control and

minimising perceived consequences. There has been a shift in diabetic care from the 'gold standard' of good glycaemic control to a management strategy that takes account of multivariate factors (Law, 2002). Good diabetic care should take account not just of blood glucose control, and the medical aspects of management but also of the psychological and quality of life issues that patients with diabetes face.

In addition to the cognitive response to illness, the present study highlighted the importance of acknowledging the patients' emotional response to illness and its association with levels of more general psychological well-being. Such findings would suggest that clinically it is important to assess and recognise both the patients' cognitive and emotional response to illness and the coping skills they possess to manage these. The relatively high levels of psychological distress that are often reported in this patient group would suggest that availability of psychological services to this group is an important aspect of their ongoing care.

Psychological approaches/interventions that explicitly assess patients' illness representations could potentially provide health care workers with a fruitful avenue to management, where psychological factors are not only important in terms of compliance with treatment but more generally in optimising patients' quality of life. Interventions aimed at modifying maladaptive cognitive and emotional representations of illness and developing adaptive coping strategies may prove to be beneficial. A cognitive behavioural approach to treatment in diabetes, outlined by White (2002), aims to promote effective self-management of the disease, thereby optimising levels of control, and to minimise psychological problems which arise as a direct result of the disease and its consequences. Although this approach has so far

not been systematically evaluated in a Type 1 population, results of a randomised control trial of Cognitive Behaviour Therapy in patients with Type 2 diabetes showed encouraging results (Lustman, Griffith et al, 1998). This psychological approach may prove a valuable resource in diabetes management.

Cystic Fibrosis related Diabetes

In terms of the clinical implications for the cystic fibrosis related diabetic group, the findings from the present study suggest that patients appear to perceive their diabetes as a secondary consequence of their cystic fibrosis as opposed to a distinct illness in its own right. This would suggest that a collaborative team approach to treatment involving attendance by both the CF and diabetic teams at a joint clinic, ideally in the same location, would provide the optimal approach to care as suggested by Moran (2002). Low perceived levels of personal control, perhaps aggravated by the lack of well-defined treatment protocols, may be addressed by encouraging the medical teams, where possible, to collaborate with the patients in determining plans for self-management.

Findings from the current study showed that as the CF disease becomes more severe, patients become more vulnerable to depression. With progressing disease, patients' lung function deteriorates, they become more susceptible to infections, requiring more frequent intra-venous antibiotics, and limitations imposed by the disease become more acute. Findings related to the impact of disease severity on psychological functioning remain inconclusive. Anderson and colleagues (2001b), in support of the current study's findings, found that better lung function was predictive of better psychological functioning. However, disease severity per se was not found to be associated with

psychosocial scores by Britto, Kotagal, Hornung, Atherton, Tsevat & Wilmott (2002) who suggested that pulmonary exacerbations rather then lung function were associated with decreased psychosocial functioning. Nevertheless, findings do suggest that as the patient's disease progresses or their condition deteriorates, they may be more susceptible to mood problems. As the disease progresses the burden of the disease increases. It is important to consider this in light of the fact that as individuals with cystic fibrosis live longer, a secondary complication of diabetes is becoming more prevalent and this condition adds to the burden of illness. Monitoring should include not just assessment of the patients' physical state but also recognition of the psychological impact of their progressing disease.

The importance of psychosocial care in cystic fibrosis has been recognised for some time and guidelines set down by the Cystic Fibrosis Trust (2002) highlight the need for accessible psychological care for patients in this population. The monitoring and assessment of patient's psychological state may be particularly important at times when the burden of their illness is increasing. This may also be a time when effective communication with staff is paramount.

4.4 Conclusions and Directions for Future Research

This study found that an understanding of the illness representations held by patients could be a valuable tool in the ongoing care of individuals with a chronic medical condition.

The role of illness representations in the psychological well-being of adults in two different patient groups, who required management of insulin-dependent diabetes, was investigated. Results from the Type 1 diabetic group found that illness representations were predictive of levels of anxiety and depression. As this finding replicates results found in previous studies, it emphasises the potential benefit of assessing patient's illness representations and addressing maladaptive beliefs, in the psychological approach to the treatment of anxiety and depression in this patient population. Perceived consequences and levels of treatment control were found to be particularly predictive of levels of depression suggesting that interventions that specifically targeted these beliefs may prove beneficial.

This study did not investigate adherence to treatment and it excluded patients who had multiple diabetic complications. Future research interested in the relationship between illness representations and outcome in adults with diabetes may benefit from widening the inclusion criteria to include patients who have developed multiple complications as a result of their diabetes and who perhaps therefore have a less well controlled condition. In addition, the relationship between illness representations and psychological well-being would be better understood using a prospective study design.

No significant statistical difference in the perceived consequences of diabetes was found between patients in the Type 1 or CFRD groups. This suggests that despite cystic fibrosis patients having experience of coping with the limitations and self-management demands of a pre-existing chronic illness, the increased burden of a secondary diagnosis should not be ignored. However, an estimate of effect size suggests that a clinically significant difference in the perception of the consequences of diabetes was apparent. This may reflect either a denial or minimisation of the consequences of diabetes in the CFRD group or simply a lack of awareness of the possible consequences of diabetes in the cystic fibrosis sample.

The majority of patients in the CFRD group attributed the cause of their diabetes to their pre-existing illness. Contrary to initial prediction, the CFRD group perceived lower levels of personal control than the Type 1 group. This study would suggest that the cystic fibrosis patients' understanding of their diabetes as a largely uncontrollable consequence or progression of their cystic fibrosis, rather than a distinct illness in its own right, may help to explain their beliefs of lower levels of control.

The recruitment of patients with cystic fibrosis related diabetes to this study was limited due to the relatively small and finite numbers of patients with this condition in the general population. The results should therefore be interpreted with caution as insufficient statistical power may have contributed to non-significant results. However, as findings from this study suggested that, on the whole, the CFRD group believed their diabetes to be a consequence of their cystic fibrosis, the focus on just one aspect of their illness ie. diabetes, may have been too narrow to allow for significant associations between illness representations and psychological well-being

to have become apparent. As individuals with cystic fibrosis live longer, the numbers of people with the condition increases, and the challenge for patients of living with this chronic illness is prolonged. Further investigation into the role of illness representations in the adaptive outcome of patients with cystic fibrosis may therefore provide a valuable contribution in efforts to improve the quality of life for these patients.

The present study suggests that it may be impossible to separate out the impact of one aspect of cystic fibrosis (eg. diabetes) from the condition as a whole. Development of a scale that allows assessment of patient's representations of their cystic fibrosis more widely may therefore be useful. The role of illness representations in adaptive outcome has been found to be significant in a number of different chronic illnesses. This would suggest that perhaps a coordinated multi-centre study, that would allow for access to larger numbers of participants with cystic fibrosis, may be appropriate in order for these factors to be investigated further in this patient population.

An important aspect of the current study is that it adds to the limited literature focussed on adults with cystic fibrosis and it acknowledges one of the additional challenges they face as they live longer with their disease. For CFRD patients, management of diabetes adds to the burden of what is already a complex and demanding condition. Although, as a group, cystic fibrosis patients appear to be relatively well psychologically adjusted, there remain individuals who are vulnerable to psychological distress and due to the dynamic and progressive nature of the disease, this distress may become more apparent at certain points upon the patient's journey. Routine psychological monitoring, assessment and where appropriate,

intervention are therefore necessary elements in the overall care of patients in this population. Routine contact with the psychologist is carried out with all attenders at the Cystic Fibrosis clinic at the authors place of work. This allows for regular monitoring, the opportunity to establish trusting relationships, and, where necessary, prompt action should this be required. In addition, it allows the multi-disciplinary team to consider all appropriate factors in the management of their patients who suffer from this multifaceted and challenging illness.

Leventhal's self-regulatory model provided the theoretical framework to this study. However, as the study did not look at the mediating role of coping in adaptive outcome, no conclusive results can be drawn, from this study, in support of or opposition to the original model. Further research that investigates coping strategies as well as illness representations and adaptive outcome is required before conclusions regarding the validity of this theoretical model can be made. Nevertheless, the importance of illness representations in exerting a direct influence on psychological outcome was supported. This suggests, as proposed by Leventhal, that the ways in which an individual represents and responds to the threat carried by illness, are important in psychological outcome.

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Appendix A

NHS
Lothian

Patient Information Sheet

Patient Views About Diabetes: Information for patients with cystic fibrosis related diabetes (requiring insulin)

You are being invited to take part in a research study. Before you decide to participate it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

What is the study about?
The study is being carried out to find out more about living with insulin dependent diabetes. We are interested in the way in which people think about their diagnosis of diabetes, and how this affects the way they feel. The study aims to better our understanding of the impact of a diagnosis of diabetes on patients' lives.

Why have I been chosen to take part?
This study is interested in the views of patients with insulin dependent diabetes. We are keen to compare the experience of two groups of patients:

(1) Patients whose diabetes is secondary to cystic fibrosis (CF), a genetic disease that causes respiratory (chest) problems and other medical complications that can be life-threatening.
(2) Patients who have insulin dependent diabetes (Type 1 diabetes) but no other serious medical conditions.

All patients registered with the Adult Cystic Fibrosis Service at the Western General Hospital, Edinburgh, who have a secondary diagnosis of insulin dependent diabetes will therefore be invited to take part in the study. A group of patients of similar age and sex to this group, but who attend the diabetic clinic (Type 1 diabetes patients) will also be invited to participate.

What do I have to do if I take part?
If you agree to take part in the study you will be asked to fill out several questionnaires when you next attend clinic. You will only be required to complete these questionnaires on one occasion.

Do I have to take part?
No. It is up to you to decide whether or not to take part. If you decide to take part and later wish to withdraw from the study you are free to do so at any time. A decision to withdraw, or not to take part, will not affect your treatment or the standard of care you receive in any way.

What are the possible benefits of taking part?
The information provided by participants may improve our understanding of the impact of diabetes on patients' lives. We hope this information will improve the support available when needed, in future.

Are there any disadvantages to taking part?
It is unlikely that you will experience any disadvantages as a result of taking part in the study. If however you did have any problems (for example, with filling in the questionnaires) please let the researcher know so that they can offer you some help or discuss any problems.

Will the information I give be confidential?
The information you provide for this study will be kept strictly confidential and only a number will be used to identify you. Your consultant and GP will be informed that you are taking part in this study.

What will happen to the results of this study?
The results of the study may be published when the study is completed. All information will have been collected by Summer 2004. Published reports will not include your name or any other information that will identify you.

Who can I contact for more information?
If you have any questions about the study or wish to discuss the study informally, please contact Paula Weeple, Trainee Clinical Psychologist with the CF Team, at the CF Office on 0131 537 1762.

If you wish to speak to someone not directly involved in the study for advice, you may contact an independent advisor who will try to deal with any queries. Dr Ron Fergusson has agreed to be the independent advisor for this study and can be contacted on 0131 537 1779.

Should you agree to participate in the study you will be given a copy of this information sheet to keep and will be required to complete the attached consent form.

Thank you for taking the time to read this information sheet.

NHS
Lothian

Patient Information Sheet
Patient Views About Diabetes: Information for patients with Type 1 (insulin dependent) diabetes.

You are being invited to take part in a research study. Before you decide to participate it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

What is the study about?
The study is being carried out to find out more about living with insulin dependent diabetes. We are interested in the way in which people think about their diagnosis of diabetes, and how this affects the way they feel. The study aims to better our understanding of the impact of a diagnosis of diabetes on patients' lives.

Why have I been chosen to take part?
This study is interested in the views of patients with insulin dependent diabetes. We are keen to compare the experience of two groups of patients:

(1) Patients whose diabetes is secondary to cystic fibrosis (CF), a genetic disease that causes respiratory (chest) problems and other medical complications that can be life-threatening.
(2) Patients who have insulin dependent diabetes (Type 1 diabetes) but no other serious medical conditions.

All patients registered with the Adult Cystic Fibrosis Service at the Western General Hospital, Edinburgh, who have a secondary diagnosis of insulin dependent diabetes will therefore be invited to take part in the study. A group of patients of similar age and sex to this group, but who attend the diabetic clinic (Type 1 diabetes patients) will also be invited to participate.

What do I have to do if I take part?
If you agree to take part in the study you will be asked to fill out several questionnaires when you next attend clinic. You will only be required to complete these questionnaires on one occasion.

Do I have to take part?
No. It is up to you to decide whether or not to take part. If you decide to take part and later wish to withdraw from the study you are free to do so at any time. A decision to withdraw, or not to take part, will not affect your treatment or the standard of care you receive in any way.

What are the possible benefits of taking part?
The information provided by participants may improve our understanding of the impact of diabetes on patients' lives. We hope this information will improve the support available when needed, in future.

Are there any disadvantages to taking part?
It is unlikely that you will experience any disadvantages as a result of taking part in the study. If however you did have any problems (for example, with filling in the questionnaires) please let the researcher know so that they can offer you some help or discuss any problems.

Will the information I give be confidential?
The information you provide for this study will be kept strictly confidential and only a number will be used to identify you. Your consultant and GP will be informed that you are taking part in this study.

What will happen to the results of this study?
The results of the study may be published when the study is completed. All information will have been collected by Summer 2004. Published reports will not include your name or any other information that will identify you.

Who can I contact for more information?
If you have any questions about the study or wish to discuss the study informally, please contact Paula Weeple, Trainee Clinical Psychologist with the CF Team, at the CF Office on 0131 537 1762.

If you wish to speak to someone not directly involved in the study for advice, you may contact an independent advisor who will try to deal with any queries. Dr Ron Fergusson has agreed to be the independent advisor for this study and can be contacted on 0131 537 1779.

Should you agree to participate in the study you will be given a copy of this information sheet to keep and will be required to complete the attached consent form.

Thank you for taking the time to read this information sheet.

NHS
Lothian

Information Sheet
Patient and Staff Views about Diabetes: Information for Staff

You are being invited to take part in a research study. Before you decide to participate it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask if there is anything that is not clear or if you would like more information.

What is the study about?
The study is being carried out to find out more about the patients' experience of living with insulin dependent diabetes. We are interested in the way in which patients think about their diagnosis of diabetes, and how this affects the way they feel. The study aims to better our understanding of the impact of a diagnosis of diabetes on patients' lives.

The study is also interested in staff views about the impact of diabetes on patients' lives and to what extent patient and staff perceptions of the impact of a diagnosis of diabetes are similar.

Why have I been chosen to take part?
All members of the Cystic Fibrosis team and the Respiratory Ward staff at the Western General Hospital are being invited to take part.

What do I have to do to take part?
If you agree to take part in the study you will be asked to complete one short questionnaire. You will only be required to complete this questionnaire on one occasion.

Will the information I give be confidential?
The information you provide for this study will be kept strictly confidential and only a number will be used to identify you.

Should you agree to participate in the study you will be given a copy of this information sheet to keep and will be required to complete a consent form.

Thank you very much for taking the time to read this information sheet.

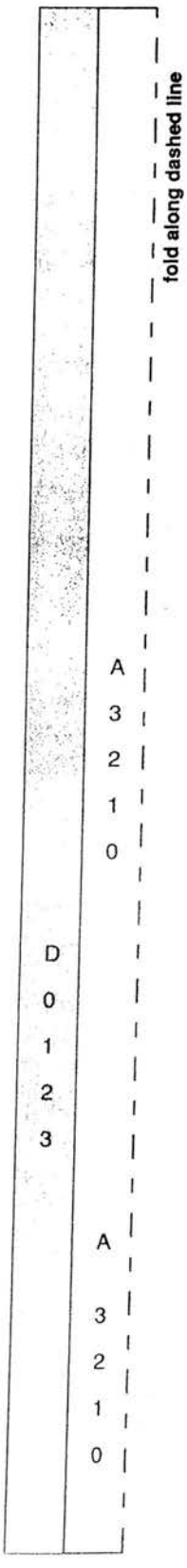
Appendix B

The Well-Being Questionnaire

Please circle a number on each of the following scales to indicate how often you feel each phrase has applied to you in the past few weeks:

	all the time			not at all
1. I feel that I am useful and needed	3	2	1	0
2. I have crying spells or feel like it	3	2	1	0
3. I find I can think quite clearly	3	2	1	0
4. My life is pretty full	3	2	1	0
5. I feel downhearted and blue	3	2	1	0
6. I enjoy the things I do	3	2	1	0
7. I feel nervous and anxious	3	2	1	0
8. I feel afraid for no reason at all	3	2	1	0
9. I get upset easily or feel panicky	3	2	1	0
10. I feel like I'm falling apart and going to pieces	3	2	1	0
11. I feel calm and can sit still easily	3	2	1	0
12. I fall asleep easily and get a good nights rest	3	2	1	0
13. I feel energetic, active or vigorous	3	2	1	0
14. I feel dull or sluggish	3	2	1	0
15. I feel tired, worn out, used up, or exhausted	3	2	1	0
16. I have been waking up feeling fresh and rested	3	2	1	0
17. I have been happy, satisfied, or pleased with my personal life	3	2	1	0
18. I have felt well adjusted to my life situation	3	2	1	0
19. I have lived the kind of life I wanted to	3	2	1	0
20. I have felt eager to tackle my daily tasks or make new decisions	3	2	1	0
21. I have felt I could easily handle or cope with any serious problem or major change in my life	3	2	1	0
22. My daily life has been full of things that were interesting to me	3	2	1	0

Please make sure that you have considered each of the 22 statements and have circled a number on each of the 22 scales.



The Hospital Anxiety and Depression Scale

Name . . . . . **Date** . . . . . .

Clinicians are aware that emotions play an important part in most illnesses. If your clinician knows about these feelings she or he will be able to help you more.

This questionnaire is designed to help your clinician to know how you feel. Ignore the numbers printed on the left of the questionnaire. Read each item and **underline** the reply which comes closest to how you have been feeling in the past week.

Don't take too long over your replies; your immediate reaction to each item will probably be more accurate than a long thought-out response.

A

I feel tense or 'wound up':

3 Most of the time

2 A lot of the time

1 From time to time, occasionally

0 Not at all

D

I still enjoy the things I used to enjoy:

0 Definitely as much

1 Not quite so much

2 Only a little

3 Hardly at all

A

I get a sort of frightened feeling as if something awful is about to happen:

3 Very definitely and quite badly

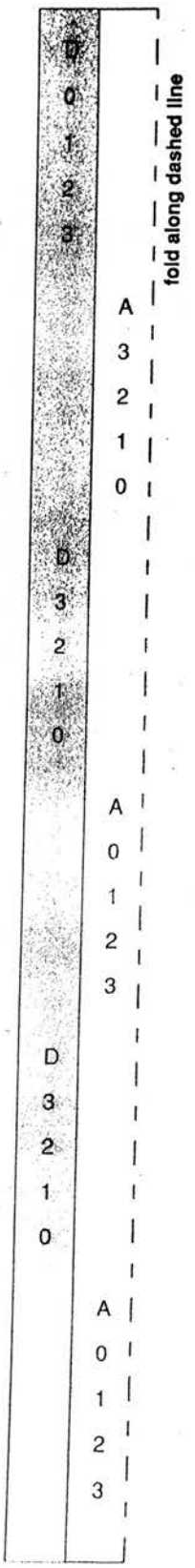
2 Yes, but not too badly

1 A little, but it doesn't worry me

0 Not at all

(continued overleaf)

THE HOSPITAL ANXIETY AND DEPRESSION SCALE



I can laugh and see the funny side of things:

As much as I always could

Not quite so much now

Definitely not so much now

Not at all

Worrying thoughts go through my mind:

A great deal of the time

A lot of the time

From time to time but not too often

Only occasionally

I feel cheerful:

Not at all

Not often

Sometimes

Most of the time

I can sit at ease and feel relaxed:

Definitely

Usually

Not often

Not at all

I feel as if I am slowed down:

Nearly all the time

Very often

Sometimes

Not at all

I get a sort of frightened feeling like 'butterflies' in the stomach:

Not at all

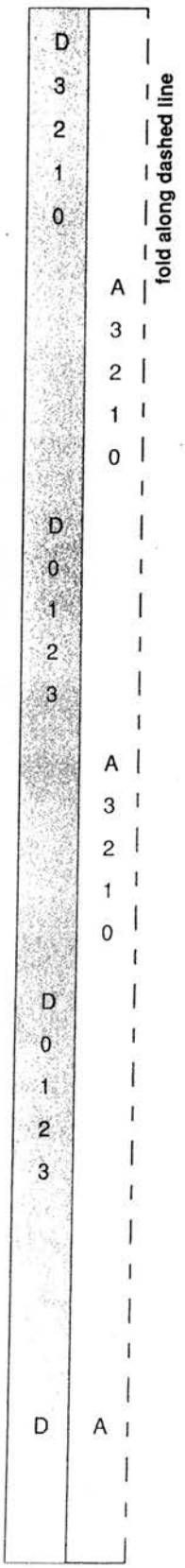
Occasionally

Quite often

Very often

(continued overleaf)

THE HOSPITAL ANXIETY AND DEPRESSION SCALE



I have lost interest in my appearance:

Definitely

I don't take as much care as I should

I may not take quite as much care

I take just as much care as ever

I feel restless as if I have to be on the move:

Very much indeed

Quite a lot

Not very much

Not at all

I look forward with enjoyment to things:

As much as ever I did

Rather less than I used to

Definitely less than I used to

Hardly at all

I get sudden feelings of panic:

Very often indeed

Quite often

Not very often

Not at all

I can enjoy a good book or radio or TV programme:

Often

Sometimes

Not often

Very seldom

Now check that you have answered all the questions

For office use only:

D : ☐ Borderline 8–10

A : ☐ Borderline 8–10

YOUR VIEWS ABOUT YOUR DIABETES

Listed below are a number of symptoms that you may or may not have experienced since your diabetes. Please indicate by circling *Yes* or *No*, whether you have experienced any of these symptoms since your diabetes, and whether you believe that these symptoms are related to your diabetes.

	I have experienced this symptom *since my diabetes*			This symptom is *related to my diabetes*	
Pain	**Yes**	**No**	_____	**Yes**	**No**
Sore Throat	**Yes**	**No**	_____	**Yes**	**No**
Nausea	**Yes**	**No**	_____	**Yes**	**No**
Breathlessness	**Yes**	**No**	_____	**Yes**	**No**
Weight Loss	**Yes**	**No**	_____	**Yes**	**No**
Fatigue	**Yes**	**No**	_____	**Yes**	**No**
Stiff Joints	**Yes**	**No**	_____	**Yes**	**No**
Sore Eyes	**Yes**	**No**	_____	**Yes**	**No**
Wheeziness	**Yes**	**No**	_____	**Yes**	**No**
Headaches	**Yes**	**No**	_____	**Yes**	**No**
Upset Stomach	**Yes**	**No**	_____	**Yes**	**No**
Sleep Difficulties	**Yes**	**No**	_____	**Yes**	**No**
Dizziness	**Yes**	**No**	_____	**Yes**	**No**
Loss of Strength	**Yes**	**No**	_____	**Yes**	**No**

We are interested in your own personal views of how you now see your current diabetes.

Please indicate how much you agree or disagree with the following statements about your diabetes by ticking the appropriate box.

	VIEWS ABOUT YOUR DIABETES	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
IP1	My diabetes will last a short time					
IP2	My diabetes is likely to be permanent rather than temporary					
IP3	My diabetes will last for a long time					

	VIEWS ABOUT YOUR DIABETES	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
IP4*	This diabetes will pass quickly					
IP5*	I expect to have this diabetes for the rest of my life					
IP6	My diabetes is a serious condition					
IP7	My diabetes has major consequences on my life					
IP8*	My diabetes does not have much effect on my life					
IP9	My diabetes strongly affects the way others see me					
IP10	My diabetes has serious financial consequences					
IP11	My diabetes causes difficulties for those who are close to me					
IP12	There is a lot which I can do to control my symptoms					
IP13	What I do can determine whether my diabetes gets better or worse					
IP14	The course of my diabetes depends on me					
IP15*	Nothing I do will affect my diabetes					
IP16	I have the power to influence my diabetes					
IP17*	My actions will have no affect on the outcome of my diabetes					
IP18*	My diabetes will improve in time					
IP19*	There is very little that can be done to improve my diabetes					
IP20	My treatment will be effective in curing my diabetes					
IP21	The negative effects of my diabetes can be prevented (avoided) by my treatment					
IP22	My treatment can control my diabetes					
IP23*	There is nothing which can help my condition					
IP24	The symptoms of my condition are puzzling to me					
IP25	My diabetes is a mystery to me					

IP26	I don≠ understand my diabetes					
IP27	My diabetes doesn≠ make any sense to me					
IP28*	I have a clear picture or understanding of my condition					
IP29	The symptoms of my diabetes change a great deal from day to day					
IP30	My symptoms come and go in cycles					
IP31	My diabetes is very unpredictable					
IP32	I go through cycles in which my diabetes gets better and worse.					
IP33	I get depressed when I think about my diabetes					
IP34	When I think about my diabetes I get upset					
IP35	My diabetes makes me feel angry					
IP36*	My diabetes does not worry me					
IP37	Having this diabetes makes me feel anxious					
IP38	My diabetes makes me feel afraid					

CAUSES OF MY DIABETES

We are interested in what <u>you</u> consider may have been the cause of your diabetes. As people are very different, there is no correct answer for this question. We are most interested in your own views about the factors that caused your diabetes rather than what others including doctors or family may have suggested to you. Below is a list of possible causes for your diabetes. Please indicate how much you agree or disagree that they were causes for you by ticking the appropriate box.

	POSSIBLE CAUSES	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
C1	Stress or worry					
C2	Hereditary - it runs in my family					
C3	A Germ or virus					
C4	Diet or eating habits					
C5	Chance or bad luck					
C6	Poor medical care in my past					
C7	Pollution in the environment					
C8	My own behaviour					
C9	My mental attitude e.g. thinking about life negatively					
C10	Family problems or worries					
C11*	Overwork					
C12*	My emotional state e.g. feeling down, lonely, anxious, empty					
C13*	Ageing					
C14*	Alcohol					
C15*	Smoking					
C16*	Accident or injury					
C17*	My personality					
C18*	Altered immunity					

In the table below, please list in rank-order the three most important factors that you now believe caused <u>YOUR diabetes.</u> You may use any of the items from the box above, or you may have additional ideas of your own.

The most important causes for me:

1. _____

2. _____

3. _____

YOUR VIEWS ABOUT YOUR PATIENTS' DIABETES

We are interested in your views of how you see your patients' diabetes.

Please indicate how much you agree or disagree with the following statements[1] about your patients' diabetes by ticking the appropriate box.

	VIEWS ABOUT DIABETES	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
1	The patients' diabetes is a serious condition					
2	The patients' diabetes has major consequences on his/her life					
3	The patients' diabetes does not have much effect on his/her life					
4	The patients' diabetes strongly affects the way others see them					
5	The patients' diabetes has serious financial consequences					
6	The patients' diabetes causes difficulties for those who are close to him/her					
7	There is a lot that the patient can do to control his/her symptoms					
8	What the patient does can determine whether the diabetes gets better or worse					
9	The course of the patients' diabetes depends on him/her					
10	Nothing the patient does will affect their diabetes					
11	The patient has the power to influence his/her diabetes					
12	The patients' actions will have no affect on the outcome of their diabetes					
13	There is very little that can be done to improve the patients' diabetes					
14	Treatment will be effective in curing the patients' diabetes					
15	The negative effects of the patients' diabetes can be avoided by treatment					
16	There is nothing which can help the patients' condition					

[1] Adapted from the Illness Perceptions Questionnaire – Revised (IPQ-R)